African and African-Caribbean Londoners' experiences of cancer services: a narrative approach

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African and African-Caribbean Londoners' Experiences of Cancer Services:
A Narrative Approach

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ABSTRACT

Cancer is a major illness in the United Kingdom with differences in prevalence, morbidity and mortality, across the population. The focus of this study is twofold: firstly, to explore African and African-Caribbean Londoners' experiences of cancer services and secondly to use a narrative approach, focused on cancer, specifically related to African and African-Caribbean Londoners, an approach that has not been undertaken previously. Therefore I also aim to explore whether such a research approach has value as a research tool for these communities. Five research questions frame the focus of the study, namely: What factors affected their experiences of cancer services? How did culture, ethnicity and societal factors influence their experiences? How do those factors influence the stories they tell and the way they tell them? What were good and bad practices which affected their experiences? What is the value of the narrative approach in research related to cancer focused on African and African Caribbeans? It is intended that this thesis will have a wider methodological relevance for BME health research, as well as relevance for BME cancer service research and provide suggestions on practical application of actions to address some challenges.

The African and African-Caribbean communities together form the second largest minority ethnic group in the UK, but health research focusing specifically on cancer related to these two communities is limited. The incidence of cancer is expected to increase amongst minority ethnic communities for a number of reasons: an aging minority ethnic population and changes in lifestyle and environment. It is therefore essential to gain a greater understanding of issues for African and African-Caribbean communities which either hinders or aids in providing an enhanced positive

experience of cancer services in London.

London was chosen because it is the most diverse, multicultural, multiracial city in the UK and hence the assumption is that it has well-developed health structures and systems in relation to cancer, which meet the diversity of its population.

Narrative research using dialogic analysis is the methodology used. The theoretical foundation for the thesis was a combination and integration of two illness narrative concepts; namely, Bury's (2001) *'moral and contingent illness narratives'* typologies is combined with Hydén's (1997) *'illness as narrative'* typology. The combination and adaptation of these typologies was to broaden those concepts to illustrate how other socially derived constructs such as ethnicity can impact on the narrative created.

Dialogic analysis, underpinned by Murray's (2000) four levels of analysis, namely, personal, interpersonal, socio-political and positional, was used as an underpinning basis to discuss the interconnections between the findings. In-depth interviews were conducted with twelve participants who were recruited through convenience and snowballing. The nine women and three men in the study originated from Nigeria, Ghana, Kenya, Trinidad and Jamaica.

The findings demonstrate that ethnicity, religion and communication play a significant part in impacting on their experiences with cancer services The narratives identify factors which reflect positive and negative experiences of the engagement of African's and African-Caribbeans with cancer services. Positive experiences of cancer services were articulated from the narratives, which included clinicians apologising for mistakes and clinicians creating an environment which encouraged a positive relationship between themselves and the patient.

Some of the challenges participants articulated have been addressed in previous research. These include: cultural insensitivity, lack of access to information on cancer services, lack of respect, feelings of powerlessness and vulnerability. However areas this research unearthed from the narratives that are not addressed elsewhere are: the power of church leaders, breast self-examination (BSE) and cultural issues associated with self examination, acknowledgement of the heterogeneity of African and African-Caribbean communities and how that is played out in health seeking behaviour and beliefs surrounding cancer. Courage and resilience are concepts which are rarely explicitly mentioned or recognised in earlier UK research, including the role black men play as carers, a subject virtually non-existent in health research.

As a qualitative research method, narrative research proved valuable in enabling an understanding of issues that affect African and African-Caribbean communities in relation to cancer and receiving cancer services. Dialogic analysis provides a basis to reveal the depth of the participants lived experience and how those experiences shape their behaviour in relation to cancer care. This thesis illustrates that like all patients with cancer, the cancer experience is an individual phenomenon. However, narratives demonstrate that those experiences are bound up in historical, cultural, social, religious and spiritual perspectives.

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CHAPTER 1: INTRODUCTION

1.0 Introduction

This thesis focuses on African and African-Caribbean Londoners' experiences of cancer services from cancer screening through to palliative care. Narrowing the scope to Africans and African-Caribbeans provided the opportunity to gain an in-depth critical account of individual experiences, the outcome of which has some implications for other minority ethnic communities. Furthermore the focus on these two communities stemmed from identifying a dearth of literature relating to cancer, specifically in relation to these two communities in the UK. Therefore this research contributes to the knowledge and understanding of African and African-Caribbean Londoners' experiences of cancer services, building on currently available literature. Narrative research is the chosen methodological and theoretical foundation for this study. To my knowledge, narrative research has not been applied to these communities in relation to cancer in the United Kingdom; hence, as part of the research thesis, I explore whether such a research approach has value as a research tool for these communities. London was the focus for this research because:

- African and African-Caribbean populations are the second largest BME group in the capital (South Asians being the largest). Seventy-eight percent of the total UK African population and sixty-one percent of the total UK Caribbean population reside in London (ONS, 2012; Szcepura, 2005).

The Nigerian diaspora forms the largest of the African communities in the UK, approximately one million (IOM, Nigeria 2007). The Jamaican diaspora is the largest of the Caribbean community, approximately 300,000 (IOM, Jamaica, 2007).

In this chapter, a general overview surrounding the complexities of multiculturalism and healthcare provision are presented, along with a succinct historical account of the attempts of the National Health Service (NHS) to address the health needs of minority ethnic communities. In addition, ethnicity and culture, in relation to cancer and the Africa and African-Caribbean communities, will be explored, to provide an understanding of the complexities of how those social constructs impact on utilisation, access and acceptance of cancer services and treatments. The core of the thesis relates to 'experiences' and this concept is discussed. Finally, an introduction to the focus of successive chapters is provided.

1.1 Cancer: the silent killer

Cancer does not discriminate; it affects all ages, races and genders. It has become a major epidemic across the globe. The latest figures for 2008 show that 12.7 million cases of people were diagnosed with cancer. In that same year, 7.6 million deaths across the globe were caused by cancer (Cancer Research UK, 2012). The most recent UK statistics indicate that 320,000 people were diagnosed with cancer in 2009. Cancer of the breast, lung, prostate and colon accounted for over half of all cases (Cancer Research UK, 2012). Extrapolating accurate data to establish the numbers of black and minority ethnic groups diagnosed with cancer, has been hampered by the lack of consistent data collection on ethnicity by hospitals (National Cancer Intelligence Network and Cancer Research UK, 2009). Since 1995, it has been compulsory for hospitals to collect data on the ethnicity of patients, but many have struggled to reach the 80 percent government target. Yet as Psoinis and colleagues (2011) stipulated ethnic monitoring is critically important as a means of improving healthcare.

Evidence from the London Health Observatory (2004) and more recently from Cancer Research UK (2008) indicated cancer is increasingly becoming a major cause of death in minority ethnic communities. The incidence of cancer is expected to increase amongst minority ethnic communities for a number of reasons: an aging minority ethnic population and changes in that population's lifestyle and environment. Clegg (2003) suggested that there has been some overall improvement in cancer care for racial and ethnic groups; nonetheless, there are still concerns regarding access and utilisation of cancer services for BME groups.

Patient groups and oncologists urged the government to take action against the high mortalities caused by cancer. They pointed to the necessity for greater consistency in cancer care practices, availability of treatments and skilled healthcare staff in cancer and palliative care. The Calman-Hine Report (1995) was a response to the rising concerns of cancer care and undertook a root and branch approach to the re-organisation of cancer services. The report was instrumental in the government's response, which was to establish the NHS Cancer Plan (DH,2000). This policy was designed to bring about radical changes to cancer care, setting out the government's strategy not only to reduce mortality but to improve survival and quality of life. The importance of cancer screening and early detection was, and still is, considered fundamental in improving outcomes and linked to these was the identification of the need to reduce inequalities through the provision of excellence in access and treatment provision for cancer. As part of the re-organisation of cancer services, thirty-four cancer networks were established across England and Wales: five of the networks are in London and the ultimate aims were to improve cancer services from prevention through to palliative care with consideration of the different cultural needs

of the population. Taking into account the level of black and minority ethnic populations in London, Trevat and Kelly (2006) discussed the lack of a consensus on how to address the needs of BME cancer patients, which potentially creates an inequitable provision of services.

1.2 Demographic changes and addressing the health needs of African and African-Caribbean communities

The increasing diversity of the UK population has created a need to address the health needs of minority ethnic communities (Bhopal, 2007). Attempting to close the gap in inequalities in health between and within communities is a major task for the NHS as each community has its own traditions, norms and health profiles presenting a myriad of difficulties. Interactions which occur between migrants and between migrants and the host community can have an impact on traditions, beliefs and customs and hence create further complexities in health and illness behaviour. Addressing inequalities in healthcare in the face of a growing multicultural population requires actions at national, local and individual level; understanding and responding to different attitudes to health beliefs and health behaviour; being cognisant of, and responding to, different patterns of diseases; effective utilisation of and access to interpreting and translating services; and healthcare professionals recognising their own biases, prejudices and stereotypical views.

Migration is dynamic and changes the composition of the host population. Migration has a significant impact on health, irrespective of social class. It is stressful, social ties are lost or become difficult and the need to re-build one's life and support structures in an alien environment is not met without difficulty (Helman, 2007;

Szcepura, 2005). The Second World War was to see the most significant change in the demographic profile of the UK (Owen, 2003). The arrival of the iconic ship *Windrush* in 1948 brought the first generation of migrant workers from the Caribbean to England. Their arrival in numbers was in response to purposeful recruiting carried out by the British government to support the rebuilding of the country. They populated posts within the newly formed National Health Service as well as being employed in blue collar occupation. The recruitment exercise by the British government was also undertaken in parts of South East Asia and Africa, but African-Caribbeans formed the greatest significant percentage of overseas NHS staff during that time. The 1970s saw the main migration of Africans, particularly from West Africa, more recently in the 1990s from the Horn of Africa with African migrants now being the largest of the black population in the UK (Office of National Statistics, 2012). Mares and colleagues (1985) suggested that although the premise of the NHS was equity and fairness, many of those from the former Commonwealth did not experience these attributes. Their experiences of racism both within the workplace and the wider host community have played a part, particularly for first generation migrants, in shaping attitudes, actions, beliefs and behaviour regarding interactions with healthcare professionals from the indigenous population.

The 1991 UK population census was the first to request information on ethnic origin. The Office of Population Census Survey (OPCS) (2001) reported the minority ethnic community at that time was five percent. By 2011 the BME population had risen to fourteen percent (ONS, 2012). The 2011 UK census presented a significant change in the demographics of London. For the first time in London, the white British population as a group are lower in number (45 percent) compared to the non-British

population (ONS, 2012). London has the most ethnically diverse population in the UK, with over 300 languages being spoken in the capital; the most common are listed in appendix one. The multiculturality of London brings with it a diversity of religions practised there. Within the African and African-Caribbean communities, Christianity (in the form of Anglican, Baptist, Catholicism, Evangelicalism, Pentecostal, 7th Day Adventists) and Islam are the most common forms of religion practised.

The demographic picture of London outlined above, would suggest that it should be one of the cities in which cancer care for minority ethnic communities is strategically well developed. However, it is the multicultural diversity of London which provides challenges to healthcare commissioners and healthcare providers to deliver equitable access to healthcare services. Equity is fundamental in reducing health inequalities, but one of the difficulties with equity is how it can be measured. Bravemen and Gruskin (2003) agreed with Whitehead's (1992) definition of equity in healthcare as:

- Equal access to care
- Equal utilisation for equal need
- Equal quality care for all (p.44)

Nonetheless they argued for a more focused definition in which equity can be more measurable and therefore a guide to accountability for action. They went on to provide a tentative definition of equity in health, which stated:

> The absence of systematic disparities in health or in the major social determinants of health between social groups who have different levels of underlying social advantage/disadvantage – that is different positions in a social hierarchy (Bravemen and Gruskin, 2003, p.254).

In essence they suggested health is interwoven with social circumstances related to housing, education and employment/unemployment; therefore social policies can affect health and do so disproportionately for those who are already considered disadvantaged (single parents, the elderly, the poor and disenfranchised, ethnic and religious groups).

Health inequity is not synonymous with health inequality. Health inequity refers to the allocation and distribution of resources which can drive health inequalities. Not having access to cervical screening services because there are no female doctors can impact on usage of that service for Muslim women or women who prefer a female doctor for such an intimate procedure (Chui, 2003). In the context of this thesis, personal narratives present an indication of how narrators perceived their care and access to treatment and services as equitable.

Successive governments over the last two decades have taken some positive steps towards addressing health issues for minority ethnic communities and striving to achieve better understanding of health inequalities, to reduce both their impact and development in minority ethnic communities. Legislative developments, including the NHS and Community Care Act (DH,1990), the NHS Plan (DH,1991), the Race Relations (Amendment) Act, 2000) and most recently the Equality Standards Act (2010) and the Health and Social Care Act (2012), are aimed at eradicating inequalities and discrimination. Independent inquiries such as the Acheson Report (1998) and the 2004 Health Survey for England conducted by Sproston and Mindell (2006) by emphasised the importance of meeting local health needs, tackling wider determinates of ill health and improving access to healthcare provision and

information. However, Healy and McKee (2004) argued policy initiatives were slow in being developed and at times services were inappropriate, ill-thought-out in their planning, were culturally insensitive and seemed to be 'add-ons', which prevented any purposeful integration. In addition, Bhopal (2007) suggested that the UK policy response over the last 50 years to minority ethnic communities' health needs has arguably been fragmented, piecemeal, uncoordinated and intermittent.

Following on from the review by Atkinson, (2006) on health inequalities in London, the Marmot Review (2011) suggested there is still much to do in addressing black and minority health needs. One area of the healthcare system which has been challenging for minority ethnic communities is primary care. Findings from the Marmot Review (2011) indicated significant differences in the quality of services received by different ethnic groups and of outcomes of treatment and healthcare. This was also the case with earlier studies (Aspinall and Jacobson, 2004; Goyder and Bootha , 2000; Smaje and LeGrand, 1997). Black and minority ethnic patients reported greater dissatisfaction with primary care in comparison with white patients.

In 2008 the Department of Health published a report, 'No patient left behind: how can we ensure world-class primary care for black and minority people?', which put forward recommendations on how healthcare professionals could improve access and service provision for black and minority ethnic communities. Many of these recommendations have yet to be implemented and, as highlighted by Williams and colleagues (2012), difficulties for minority ethnic communities with primary care services have still to be overcome. In particular, they found black men had little understanding of what primary care was or what it had to offer and structural

constraints, such as racism, influenced the men's perceptions of access to health services. Earlier work by Karlsen (2007) reported similarly that racism was not only a cause of illness but impacted on access and hence played a role in exclusion from welfare resources.

Primary care is pivotal to accessing other health services. It has been suggested that access to primary care in urban areas like London is problematic for a number of reasons including lack of awareness of services, challenges with access, perceptions by BME patients of healthcare professionals' lack of cultural understanding, and organisational barriers (Amlak, 2010; Nazarko, 2011). These are fundamentally significant considerations in cancer care when early diagnosis and timely interventions are critical to survival. Late presentation can be related to lack of awareness of symptoms associated with an illness compromising efficacy of treatment. This indicates the importance healthcare practitioners have in cancer awareness programmes and being creative in how they engage with BME communities.

1.3 Ethnicity, culture and their impact on cancer

Ethnicity as a socially constructed concept has been under scrutiny and debate for many years, with researchers using different elements to frame a definition. Ethnicity by some theorists is perceived as interwoven with culture and being a fundamental premise on what shapes the individual (Rex and Mason, 1986). Wallman (1986) argued that ethnicity is dependent on and relates to boundaries created between ethnic groups. To have such a boundary would suggest groups of individuals must share some commonality of cultural heritage, traditions and descent. Ruokonen-

Engler (2009) articulated the necessity of understanding why ethnicity is important because of the differentials in terms of social positioning, power relations, structural constraints ethnicity created between individuals and ethnic groups within society. Earlier work by Yuval-Davis (2006) articulated her perception on the importance of ethnicity as a significant element in social relationships, stating:

> Differential social positioning in terms of class, race, ethnicity, gender and so forth, tend to create in specific historical situations, hierarchies of differential access to a variety of resources –economical, political and cultural (Yuval-Davis ,2006, p.199).

In addition, colonialism, oppression and migration are factors I believe cannot be ignored in the debate on ethnicity and social inequalities as they undoubtedly have a bearing on health and illness. Personal histories and life experiences interact to frame identities, prejudices and judgements.

Ethnicity as a concept has changed over time but includes features of skin colour, place of birth, nationality, experience of migration, language, religion, culture or 'race'. In the context of health and healthcare, other additional attributes include genetic inheritance and ancestry, diet, dress and other aspects of lifestyle (Johnson, 2003). In this thesis, ethnicity is defined as meaning shared culture, traditions and norms, within which there is a commonality of language and a shared historical past. Ethnic identity can be situational depending upon what objectives are to be achieved and who is asking the question (Mason, 1995). On a government census form, a person may classify themselves as black Caribbean, but in a social situation may state their identity based on their place of birth. The level of acculturation by second and third generation immigrants with the host community can create additional difficulty in classifying ethnicity.

Everyone, including those from the white community, has an ethnic identity, but the term 'minority ethnic' has carried with it connotations of negativity and marginalisation. The word 'ethnic' can denote 'other', demarking there is a cultural difference from the host population and although there are white non-British ethnic groups in the UK (Australians, Eastern Europeans) they are not readily identifiable as ethnic groups. One key criterion which provides an obvious difference between ethnic groups and therefore individuals in the UK is skin colour. If skin colour is made to be a significant factor of being designated to a certain ethnic group, without any contextual basis of currency of residence within the UK, and in the absence of a clear definition of ethnicity, it can impact negatively on a sense of belonging and acceptance by the indigenous community (Jenkins, 2008).

Ethnicity is a highly complex and at times an emotive phenomenon. Across varying definitions ethnicity is recognised as a key determining factor in health and relates to prevalence of disease, incidence, morbidity and mortality within a population (Ahmad and Bradby, 2007). Therefore ethnic monitoring is an essential armoury in addressing health inequalities. Ethnic monitoring is defined as, 'the systematic collection of ethnicity data' (London Health Observatory, 2010). It is valuable as a means both to understand and implement effective measures to address health inequalities. The collation of ethnic data is strategically important to break what the London Health Commission (2003) had called the 'cycle of invisibility'; this essentially implies that the lack of data can lead to a belief that there is not a problem that requires management. This can then result in inadequate resourcing. In addition, lack of engagement of health services by BMEs has been interpreted by

some healthcare professionals as lack of interest and Larbie and colleagues (1987, p.1) eloquently challenged such an assumption stating:

> Health professionals need to recognise that a patient's lack of expertise in professionally defined matters is matched by their own ignorance of the patient's beliefs, values and customs.

By using ethnicity data intelligently, effective targeting and efficient use of resources, which take account of cultural considerations, have a greater potential in addressing health needs. Simply providing a service to all does not guarantee equality if steps have not been taken to ensure service users will make use of the service. Being aware, for example, of the high incidence of prostate cancer in African-Caribbean men, who have comparatively low GP consultation rates, warrants creative thinking in how best to target these men.

Fulton (2010) highlighted there were pockets of good practice but collation of ethnic monitoring data remains inconsistent and what data is available is not used to inform healthcare. Relating the importance of ethnic monitoring to cancer, it is evident that not having adequate data sources challenges the ability to gain accurate cancer incidence and prevalence intelligence (Birmingham, 2005; National Cancer Intelligence Network and Cancer Research UK, 2009; Papadoulpoulots and Lee, 2004). However, it is known that there are differences in cancers which have disproportionately higher rates in African and African-Caribbean communities than the indigenous population (see Table 1.1).

Table 1.1 Common cancers in African and African-Caribbean communities.

Prostate cancer	More common in black men
Cancer of the stomach	More common in black population
Multiple myeloma	More common in black population
Adult T-cell leukaemia (HTLV-1)	Disproportionately high in Jamaicans
Cancer of the cervix (related to HPV)	More common in black women
Cancer of the bladder due to the parasite Schistomiasis	Common in Africans
Cancer of the uterus	More common in black women
Incidence of breast cancer	Incidence lower in black women but they have a higher mortality rate, in part due to late diagnosis and aggressive nature of the disease in some women

(Cancer Research UK, 2007; Hughes-Jones and colleagues, 2009; Szcepura, 2005).

Although cancer affects all groups, there are specific cancer sites which have a racial and ethnic bias. Black men are twice more likely to develop prostate cancer than any other race (Chinegwundoh and colleagues, 2006). Black people have a higher than average mortality from colon and rectal cancers (Hughes-Jones and colleagues, 2009). Multiple myeloma is more commonly seen in black men and cervical cancer, which is associated with the Herpes Pappilloma virus (HPV), is more commonly seen in black women. Breast cancer has a lower incidence in black women, but they have a higher mortality than white women (Cancer Research UK, 2008). Knowledge of these facts should strategically focus local healthcare attention

on preventative screening, where appropriate (breast, cervical) and the provision of information to communities. However, there is evidence that clinicians (particularly GPs) have a lack of understanding and awareness of these issues which can be a major problem as it leads to delay in accessing therapeutic interventions (Elkan and colleagues, 2007).

Culture and ethnicity are interrelated and their role in cancer is a significant factor in individual behaviour. Culture is a socially constructed phenomenon, which contains folklore, history and unwritten rules of how individuals interact with each other within and between groups. These lead to differences in cultural patterns and can be the foundation for a hierarchical basis of cultural oppression which is interrelated with race and ethnicity (Collins, 2000; McCall, 2005). It is essential to pay attention to these interconnections in relation to health as Viruell-Fuentes and colleagues (2012) articulate in their research. By doing so, this will enable a move away from 'blaming' the individual for their ill-health and lack of engagement with health professionals because of their cultural framework and instead create an intellectual environment in which healthcare professionals address how multiple dimensions of inequality intersect to effect health outcomes.

Defining culture is as complex as defining ethnicity but there are inseparable interconnections between ethnicity, culture and health. Leiniger's (1991, p.47) classical work defined culture as:

> Learned, shared and transmitted values, beliefs, norms and life ways of a particular group that guides their thinking, decisions and actions in patterned ways.

Leiniger's definition, Gregg and Saha (2006) suggested, is valuable, but in a time of increased migration, where there is an inevitability of being exposed to other cultures within a multicultural society, there is no one culture left unaffected in some way by the exchanges of interactions between ethnic groups. I agree with Gregg and Saha (2006) but there are ethnic boundaries based on culture which continue to exist and those cultural differences have an impact on social and health inequalities. Being a member of a minority ethnic community, means navigating between their own and the host culture, creating a multiplicity of roles and social relationships.

Cultural attitudes and individual beliefs to illness affect reactions and responses to cancer; a black Caribbean woman of Jamaican descent who is for example by profession a qualified nurse, is diagnosed with cancer, will have cultural values from both her ethnic background and from her profession. These may be contradictory or complement each other and she has to negotiate between them. The one which takes precedence depends on the circumstances she finds herself in. Dein (2004) articulated how culture provides a medium for the different ways in which individuals understand cancer, how they explain its occurrence and gives a basis for their attitudes towards cancer and life. However, focussing solely on culture to explain behaviour in illness detracts from other socio-economic determinants which in themselves, Viruell-Fuentes and colleagues (2012) point out, can play a major part in that behaviour. This illustrates the multidimensional dynamics associated with illness in which ethnicity plays a powerful role.

Culture can impact on how a person manages the sense of loss of control one feels when diagnosed with cancer. Loss of control is a significant concern and as Crossley stated when being given the diagnosis of cancer, people are:

> 'immediately shocked out of the complacency of the assumed futurity of their existence and their whole conception of themselves, their life and their world is likely to undergo radical changes' (2003, p. 440).

Stigma, taboo, myths, fear of pain and feelings of powerlessness can hinder access to and hence cause delay in diagnosis and treatment (Daher, 2012). There can be wider consequences of being diagnosed with cancer beyond the individual which create difficulties. Stigma has the ability to create silence, thereby complicating efforts to increase awareness of cancer. Cultural beliefs of cancer being contagious, a form of punishment, are not uncommon perceptions held by some black and minority ethnic groups as well as some white people (Ajose-Adeogun and Qureshi, 2012).

In some African cultures, less so in Caribbean cultures, spiritual, divine intervention, divine punishment and a belief in ill-will, are seen as factors associated with developing cancer and therefore the maxim follows that holding such beliefs may prevent a person attending for cancer screening (Powe and Finnie, 2003; Scanlon and Wood, 2005; Straughan and Seow, 1998). A cycle of self-fulfilling prophecy can be created leading to fatalistic attitudes about cancer and inevitability of death. The cycle starts with late diagnosis due to late presentation to the clinician with symptoms. The late diagnosis compromises potential benefits of treatment and therefore survivorship is compromised and mortality is high. Without improvements in increasing awareness and individuals acting on the information for the need for early diagnosis and undertaking cancer screening, this cycle is difficult to break.

1.4 The concept of 'experience'

As indicated earlier, the focus of my research was on narrators' experiences of cancer services and Andrews (2000) eloquently depicts the value of personal narratives in relation to learning from experiences:

> Personal narratives not only describe experiences, they give shape to that experience (Andrews, 2000, p. 77).

Stories, as Andrews 2000) pointed out, represent experiences, but what is 'experience'? Scott (1991) alluded to contradictions and challenges faced by historians in considering the concept 'experience'. She argued how historians' records of 'experiences' can be from fundamentally diverse epistemological perspectives. Orthodox historians, she suggested, who decontextualise experience (that is, set aside language, history and how individuals begin to be seen as different), lose the opportunity to learn and understand how difference is established. Making invisible these issues in relation to experiences is to ignore key parameters which shape experiences and Scott (1991) drew attention to the unpleasantness of what experiences can expose when she stated:

> Making visible the experience of a different group, exposes the existence of repressive mechanism...we need to attend to the historical processes that, through discourse, position subjects and produce their experiences. It is not individuals who have experience, but subjects who are constituted through experiences (Scott, 1991, p.779).

Scott's account of the significance of experience converges well with Andrews's (2000, 2007) premise about stories; that is, experiences are shaped through interactions which are influenced through history and socio-cultural dynamics. Since the focus of my thesis is based on African and African-Caribbean communities, who are minority ethnic groups, known to have historical issues in relation to migration,

racism and discrimination, their stories about cancer care drew attention to negative as well as positive experiences, made 'visible' by this thesis.

Interest in researching cancer and the black community is both personal and professional. I am passionate about my nursing specialist field which is haematology. It is a vast, dynamic and exciting area of nursing and it encompasses both malignant and non-malignant haematology. The blood cancers are leukaemia, lymphoma and multiple myeloma. Over the years in teaching the subject, it became evident from students' comments who cared for African and African-Caribbean people with cancer they wanted to provide the best care, but lacked insight into cultural perspectives which can impact on actions and reactions by Africans and African-Caribbeans. On a personal level, three of my best friends died from cancer before the age of fifty. I also lost my mother-in-law and brother-in-law to cancer.

I observed behaviour by some healthcare staff and anecdotal evidence from family, friends and colleagues, of their experiences which in the main were positive. However, there were periods when they were frustrated with the care they received, or saw being provided, it sometimes appeared to them cultural needs were not being considered. Those experiences and stories from colleagues led to my drive of wanting to delve further into this area of cancer experiences of African and African-Caribbeans, to learn from their to aid in generating a greater understanding of cancer experiences for these communities.

1.5 The Research Questions

In aiming to explore the experiences of cancer services from the perspectives of African and African-Caribbean Londoners, the following research questions framed the focus of the research study:

- What affected their experiences of cancer services?

- How did culture, ethnicity and societal constructs influence their experiences?

- How did culture, ethnicity and societal constructs influence the stories they told and the way they told them?

- What were good and bad practices which affected their experiences?

- What is the value of the narrative approach in research related to cancer focused on African and African-Caribbeans?

In addition, within these questions there are sub-categories. These indicate:

- Reactions to the diagnosis of cancer

- The impact of the diagnosis on relationships with family, friends, their communities

- Coping strategies adopted to manage the effects of treatment and long-term consequences of cancer and the treatment

1.6 Outline of the thesis

Having set the scene and described the scope of the thesis in this chapter, a brief account on each of the other chapters is outlined.

Chapter 2 - Literature review

The purpose of this literature review is threefold: first, to explore literature related to cancer and African and African-Caribbean communities; second, to examine

research methodologies used to research this topic; and, finally, to identify gaps in the literature to place this thesis in context with previous research. A critical account of the literature illustrates a common thread demonstrating regardless of methodology and theoretical underpinning used by researchers, lack of explanation and information, poor communication, GPs being barriers to accessing services, the gross lack of ethnic data to develop better intelligence regarding diversity, equity, equality, disparity were evident. Most studies focused either on screening or on a particular cancer site or generally on ethnicity or palliative care and few included both genders in their research. This thesis focuses across screening to palliative care taking a narrative approach which has not been used in the UK literature and hence the thesis treaded on uncharted ground. Religion, culture and communication were areas found relevant in the papers reviewed but the thesis explored the meanings of these concepts from the individual narrator's perspective.

Chapter 3 - Narrative Research: Illness narratives

This chapter explores accounts of illness narratives as a genre within narrative research. These accounts aim to harness meanings of interpretations of illness as told by the narrator. The theoretical foundation for this thesis was a combination and integration of two illness narrative typologies; namely, *Moral and contingent illness narratives* (Bury, 2001) with *Illness as narrative* [type] (Hyden (1997). Dialogic analysis was the method used for analysis which was influenced by Bakhtin (1986) and Riessman (2008). The typologies were broadened to incorporate ethnicity, illustrating that socially derived constructs such as ethnicity can impact on the narrative created. Ethnicity can play a significant part in illness narrative and it is of particular relevance when researching narrators who are from minority ethnic

communities; this enables understanding of the part it plays in shaping the story being told. Narrative research has its challenges and critics which are examined, along with debates on the questions surrounding the validity, 'trustworthiness' and lack of objectivity of narrative research.

Chapter 4 - The Research Process

This chapter revisits the research questions and details the process for conducting the research, issues surrounding narrative ethics, gaining ethics approval, recruitment and data collection. Twelve participants, nine women and three men took part in the research. Participants were from Ghana, Jamaica, Kenya, Nigeria and Trinidad. A combination of convenience and judgement snowballing were used to recruit to the study. In-depth interviews were undertaken and the approach taken in transcribing was presented along with the rationale for adaptation of Braun and Clarke's (2006) framework to identify the narratives' themes. Five narratives were identified which were; narratives of reliving the cancer diagnosis; narratives of healthcare professional-patient communication; narratives of culture, ethnicity and race; narratives of religion, spirituality and faith; narratives about screening. Positionality is also explored in relation to the participant and the researcher.

Chapter 5 - Findings Part I: Narratives on Cancer Diagnosis and Narratives on Religion, Spirituality and Faith

The scene is sent in this chapter for presenting the analysis of the data between this chapter and Chapter Six. Each participant's journey was unique, but commonalties were observed across the stories which provided some degree of generality between the narratives, leading to the identification of narrative themes. A snapshot of each participant is presented, the aims being twofold: to provide the reader with a 'picture' of each narrator, with the intention of assisting in 'recognising' participants and to

enable readers to relate the analysis to them as individuals. Detailed analysis on two of the narrative themes – 'reliving, the cancer diagnosis' and 'religion, spirituality and race' is subsequently presented.

Chapter 6 - Findings Part II: Narratives on Communication and Ethnicity

This chapter presents the analysis of three of the narrative themes; 'healthcare professional-patient communication on cancer', 'screening' and 'culture, ethnicity and 'race', in the same format as Chapter Five. The interconnections between communication and ethnicity and how ethnicity plays a significant part in cancer experiences is discussed. How culture, ethnicity and societal constructs influence cancer experiences, how those constructs influence the narrators told and the way they tell them and what were good and bad practices which affected their experiences are articulated. The complexity of ethnicity and its associated links with racism and prejudice are borne out in the narratives.

Chapter 7 - Discussion and Conclusions

A critical discussion of the interpretations from the findings chapter, using Murray's levels of analysis, is presented. Murray's levels of analysis; namely, personal, interpersonal, socio-political and positional, were used to present a coherent discussion of interrelated connections between the narrative themes. The discussion is presented under the sub-headings of: courage, strength and resilience (personal level); culture, ethnicity, race (socio-political level); black men as carers (socio-political and personal levels); religion and the power of church leaders (socio-political level); talking to 'me', the carer (personal level); personal narratives and their place in researching African and African-Caribbean communities. The chapter summarises the thesis, returning to the research questions, drawing together, the benefits and

challenges of narrative research, the value in the depth of the stories which were enriching and from which new knowledge was gained.

CHAPTER 2: LITERATURE REVIEW: CANCER HEALTHCARE AND BLACK AND MINORITY ETHNIC COMMUNITIES

2.0 Introduction

The previous chapter provided an account of the background, rationale and aims of this thesis. This chapter turns to exploring the valuable research specifically related to the cancer services experienced by Africans and African-Caribbeans. The objectives of my review was to scrutinise how previous researchers have approached exploring ethnicity and access to cancer services; and from the perspectives of Africans and African-Caribbeans, what research has been undertaken, examining how interrelations between those communities and healthcare professionals shape Africans and African-Caribbeans' experiences of cancer services. Furthermore, exploring experiences of Africans and African-Caribbeans living with cancer or caring for a loved one with cancer from an international perspective, provided some insights into similarities and differences of experiences of healthcare meeting the needs of black people living with cancer. Conducting a cross-cultural review of the literature enabled an exploration of reviewing whether there were commonalities of experiences of healthcare for Africans and African-Caribbeans, thereby developing a critical account of cancer experiences for these communities, which added to shaping the focus of my thesis.

Thus the purpose of this literature review is threefold: first, to explore literature related to cancer and African and African-Caribbean communities; second, to examine research methodologies used to research this topic and finally, to identify gaps in the literature to place this thesis in context with previous research. The format of the chapter is based on four themes identified from the literature.

2.1. Cancer and African and African-Caribbean communities

There is a dearth of literature on cancer and African and African-Caribbean communities in the UK. The majority of the research is focussed on South-Asian communities, whilst other studies relate to minority ethnic groups as a whole. The paucity of research in African and African-Caribbean communities in the UK has therefore in itself justified the need for the focus of this thesis on black communities and their cancer experiences. In addition, as a researcher sharing the ethnicity of those interviewed for this thesis, there are potential benefits of being an 'insider' as indicated in some of the reviewed literature (Karbani and colleagues, 2011; Randhawa and Owen 2004). Although there is diversity between and within African and African-Caribbean communities, the shared African-origins of myself and the participants can be helpful, particularly when researching a subject such as cancer which is a culturally sensitive issue in some communities.

The differences in methodology, aims, outcomes and sample size of the research studies meant a 'narrative synthesis' was undertaken as opposed to meta-analysis, which Cook and colleagues (1997, p.365) suggested is an acceptable approach to literature review when research papers have various focus, aims and use different methodologies. This led to an analysis of the papers with regard to identifying both the strengths and weaknesses of the research and enabled me to identify the value of the research and the gaps warranting further research, thereby providing a platform for my thesis. Appendix two provides a synopsis of the research papers which were reviewed. Four themes were identified from the literature and they shaped the organisation of the chapter. The themes were:

- Ethnicity, access and cancer services

- Cancer screening

- Cancer healthcare: meeting the needs of black and minority ethnic communities

- Palliative care and BME communities

Reviewing the literature under a theme is valuable for several reasons: first, it provided an opportunity to be clear about the specific characteristics of each study to avoid over-generalising on areas such as gender, socio-economic status (SES) and national backgrounds; second, my thesis explores the cancer journey and these themes cut across the cancer pathway, which enables identification of interlinks of findings between the literature, thereby facilitating recognition of gaps in the literature.

2.2 Ethnicity, access and cancer services

This section reviews literature which focuses on what impact ethnicity may have in relation to cancer services experiences for African and African-Caribbean experiences. Ethnicity as a variable is a complex concept, compounded and complicated by socio-economic, cultural factors and individual experiences of racism, all of which impact on the quality of health service experiences. The importance of the SES and its association with ethnicity, equality and equity have been debated with varying conclusions, as illustrated by studies by Smaje and LeGrand (1997) in the UK, Thomas and colleagues (2009) in Canada and Becker and Newsom (2003) in North America.

Smaje and LeGrand (1997) and later research by Szcepura (2005) sought to explore how well healthcare provision addressed equity, which is a central platform for patients to have fair access to healthcare. Smaje and LeGrand (1997) undertook a review using quantitative data to investigate the level of equity in NHS treatment received by different ethnic groups, using the General Household Survey between 1984 and 1991. They examined whether the NHS provided equal treatment for equal need. Until their study there was limited focus on the issue of ethnicity and equity; earlier research often used social class as the variable to explain NHS usage. Using the use/need ratio enabled comparisons to be made between ethnic groups in relation to the amount of health service resources used, relative to need, was based on self-reporting.

The authors' conclusions are of importance in considering access to cancer services as they identified there were systematic differences in the utilisation of health services raising what the researchers articulate is a continuing need for attention to ethnic patterns in healthcare utilisation. The authors identified a contradiction between the high levels of GP consultation by Pakistani men which did not correspond to the comparative level of accessing secondary care. The authors postulated from a socio-cultural perspective whether the over utilisation by Pakistani men is related to being in receipt of poor care or whether it is a result of poverty which is associated with poor health. Pakistani women reported lower levels of utilisation when compared to Pakistani men and their white counterparts, whereas Caribbean women reported higher GP consultation levels than the white population and Caribbean men. Caribbean men were infrequent users of GP services, a finding similar to that of Thomas and colleagues (2009) and Curtis and Lawson (2000).

Whereas Smaje and LeGrand (1997) generally focused on equity with regards to access and utilisation, Szcepura (2005) conducted a literature review specifically focussing on cancer care in relation to access and service provision. Szcepura (2005) reviewed 101 papers and used a case study approach focusing on breast and cervical screening, two conditions likely to be salient to my study. Szcepura (2005) demonstrated poor access to healthcare by BME communities and evidenced disparities in access for BME groups and the need for healthcare professionals to be more culturally aware, both in approach and delivery of care. In addition, he purported that linguistic competence and cultural competence are important if healthcare professionals are to both meet the needs of their patient groups and effectively respond to health needs of the patient. He argued the continual developments in demographic changes of the UK added to the complexity of meeting the diverse needs of the population and suggested legislative changes will challenge healthcare professionals to adapt services in order to make them equitable to the population as a whole.

The difference in usage of NHS services between Caribbean men and women, identified by Smaje and LeGrand (1997), is of significance in relation to chronic illness. Curtis and Lawson (2000) explored this issue in their study undertaking a qualitative and quantitative study to examine self-reported health concerns, with particular reference to differences between Caribbean men and women. They pointed to the difficulty of using solely quantitative data related to morbidity across genders and ethnicities arguing how questions are asked can lead to variations in answers, which can be contradictory. The quantitative element of the study utilised data collected from Sample of Anonymized Records (SAR) obtained from the 1991

census of individuals living in inner London who had indicated their ethnic group as being either white or Caribbean. The age range was 25-64 years and the SAR data was based on 10,631 women and 9,823 men. The data for both genders was analysed separately.

Age, standard of living and marital status were significant in illness reporting for men. The authors identified older men, men who were single and living in conditions classified as 'poor', as the most likely to report illness and controlling for socio-economic factors, there was no difference between white men and Caribbean men. For women, age, marital status and standard of living were also significant in illness reporting. Women who were divorced, separated, older women and those living in conditions classified as 'poor', were most likely to report illness. However, between white and Caribbean women, there was a significant reporting difference, with a higher number of Caribbean women reporting illness than white women, a finding which concurred with Smaje and LeGrand (1997). This difference raised interesting questions with the authors wondering whether illness was experienced differently or whether it was reported differently. I would suggest such questions cannot be answered by quantitative analysis, as it does not extrapolate meaning behind action or inaction.

The qualitative aspect of the study collected data from focus groups, divided by age and gender; two groups of women over 50 years, two groups of men over 50 years and one group of women aged between 30-50 years. In addition, in-depth interviews were undertaken on a selected number of participants, taken from the focus groups. The authors found there was a gender difference in how people perceived illness

and therefore how they would report it. Men produced functional, practical accounts, an approach aligned with the view of bio-medicine, whereas women took a more holistic view of health, encompassing emotional and psychological as well as physical attributes in their illness accounts. Taking such a position may account for the higher levels of minor psychosocial illnesses reported by women and reported on in the earlier work of Smaje and LeGrand (1997). However, Curtis and Lawson (2000) provided possible explanations for these differences which included: the burden placed on women by gender specific roles, the stress of sustaining multiple roles, a patriarchal society with women having a more inferior power role to men. These facets which could be bound up in intersectionality and are important but they cannot be discussed outside the context of socio-economic and education levels, of African and African-Caribbean women and the additional burden of 'race'. Older people in the study had significant reservations about completing questionnaires for surveys which the authors reflected was, in part, due to older peoples' experiences of racism, and related distrust of government organisations. They were concerned that identifying their ethnicity might mean receiving poor treatment or lead to problems in accessing services or their information being used against them. Experiences of racism by both older Caribbean men and women were therefore seen as a factors associated with illness.

Race and ethnicity play a significant part in healthcare interactions and the study by Becker and Newsom (2003) was to carefully link these concepts to an individual's financial status and to healthcare utilisation and satisfaction. Their qualitative study was to investigate racial disparities in healthcare comparing satisfaction with healthcare between individuals with low- or middle-income status. The research took

place in North America and participants aged between 21 and 63 years who had one or more chronic illness was recruited. Data were collected from in-depth interviews of 60 African-Americans, through semi-structured interviews which were conducted with each participant being interviewed three times over a 12-month period. SES was based on income history occupation, medical insurance, current status and living arrangements as well as age and gender. In conjunction with thematic coding categories, narrative analysis was also used to present narrators' experiences from which the authors concluded levels of satisfaction were related significantly to income and the healthcare sector the participant was in.

Participants from low SES reported considerably lower levels of satisfaction with healthcare. In addition, the authors suggested that dissatisfaction with healthcare caused by factors such as mistrust and bureaucracy led to delays in seeking healthcare advice. These findings are similar to Curtis and Lawson (2000) in the health behaviour of the African-Caribbean UK population, which suggests historical interrelationships between the black community and the indigenous community interplay in creating negative experiences for the black community. Becker and Newsom (2003) also suggested there are multiple factors which impact on satisfaction with healthcare but SES, because of its association with having the ability to afford health insurance, is a major factor which, they argue, cannot be ignored.

Whether participants were on low or middle SES, there were issues related to lack of satisfaction with healthcare and the authors concluded that ethnicity and social class are not exclusive and both should be considered when addressing satisfaction with

healthcare. This particular finding of their study resonates with the findings of Thomas and colleagues (2009) who also stipulate ethnicity plays a major part in satisfaction with cancer services.

Aiming to explore relational links between ethnicity and patient satisfaction with specific reference to cancer care, Thomas and colleagues (2009) conducted a quantitative study in one Tertiary Cancer Centre in Calgary Canada. Six hundred and fifty-three participants were recruited and the ethnic makeup of participants was White, First Nation/Inuit, African-American, Pacific/Islander, Latino/Hispanic and fifteen others not explicitly named. Data was collated from the Patient Satisfaction Questionnaire-III (PSQ-III) and the authors suggested that socio-demographics did not have an effect on patient satisfaction with interpersonal or continuity care. However, ethnicity was a key predictor of satisfaction with cancer care. They pointed out that non-white patients scored lower on seven out of twelve satisfaction variables. Their study highlighted a considerably strong association between ethnicity and patients' satisfaction with cancer care which, they concluded, is significantly, if not more important than age, education, SES and disease severity. Their findings concur with the conclusions of Becker and Newsom (2003), which indicated even those African-Americans who were classified as middle-income SES and had medical insurance, still reported dissatisfaction with healthcare provision.

2.2.1 Summary

The literature has outlined how ethnicity may affect utilisation of services, how different ethnic groups and gender access healthcare. In particular, how African and African-Caribbean people may talk about illness, depending on whether the

'audience' is an important focus that a researcher to be cognisant of. The complexity between ethnicity versus SES and healthcare was evident from both Smaje and LeGrand (1997) and Thomas and colleagues (2009). Although studies were conducted within different healthcare organisational structures (UK, Canada, North America), they illustrated similar challenges faced by the BME communities.

This thesis looks through the eyes of individuals themselves to examine their observations on whether their ethnicity impacted on the care they received, whether their ethnicity played a part in intercultural communication between themselves and healthcare practitioners. How culture, ethnicity and societal factors influenced experiences and in how those experiences are articulated, offering perspectives which can add to our understanding and reshape awareness of and identify different contextual attributes to those experiences, particularly related to cancer care.

2.3 Cancer screening

Currently there are three cancer screening services available in the UK (breast, cervical and more recently colorectal). Evidence demonstrates that early detection of cancer can improve morbidity and survival rates (NHS National Screening Programme, 2011; Swan and colleagues, 2003). The literature reviewed in this section focuses on breast and cervical screening. Colorectal screening is becoming established and hence research studies are woefully limited in general and specific studies related to BME communities are under-researched. Understanding what affects decision-making in accepting and accessing cancer screening services for BME communities have been discussed, with similarities in conclusions drawn from

findings in work by Box (1998), Chui (2004) Littlewood and Elias (2000), Pfeffer (2004).

Awareness of the availability of cancer screening services is paramount to access and Box (1998) conducted a qualitative study in East London, recruiting 172 black and minority ethnic women to identify their level of cancer awareness and to ascertain their knowledge and opinions regarding cervical screening. Questionnaires were used for data collection and seventeen of the women were also individually interviewed. In addition, two focus groups were formed of eleven session facilitators and eleven health advocates.

The study concluded low attendance for cervical screening was due to socio-cultural grounds such as language difficulties, fear of catching cervical cancer due to what the women perceived were problems with hygiene (related to behaviours of professionals in the environment of a GP surgery), cervical screening being associated with promiscuity, health service lack of providing translational material and physical concerns of discomfort and embarrassment. Box (1998) does not address the issue of lack of representation of black women but the title and focus of the study suggested it should include black women. Findings are therefore unrepresentative of these women and misleading titles are a particular problem found in other studies reviewed (Elkan and colleagues, 2007; Lanceley and Cox, 2007; Scanlon, 2004).

Like Box (1998) investigating attitudes to cervical screening in BME women, McCaffery and colleagues (2003) took a specific focus to examine attitudes to

human papillomavirus (HPV) testing and to explore the diversity of issues surrounding HPV testing in Greater Manchester. Unlike Box (1998), their study included white women, providing the authors with the opportunity to ascertain wider comparative data across ethnic groups. Seventy-one women of Pakistani, African-Caribbean, Indian and white British formed the sample and focus groups were used for collecting the data.

The findings highlighted four themes: upset, stigma and confusion, impact of testing positive for HPV, communicating unwanted messages and importance of information about HPV. The researchers found different reactions between the groups of women if they were to receive a positive HPV test. The African-Caribbean women and white British women took a positive approach knowing that something could be done about it, whereas Indian and Pakistani women displayed great distress and anxiety if a positive result was found. Of particular concern for the South Asian women, which was also identified in the study by Box (1998), was the fear and mistrust coupled with infidelity and promiscuity due to the testing which might be negatively perceived by partners, family and the wider community. For a South Asian woman, the potential cultural ramifications related to marriage if she is not considered to be a virgin and the perception, given if attending for HPV testing, that she has engaged in pre-marital sex, were of particular concern to taking part in HPV testing.

The research findings were important as they uncovered the psychosocial impact of HPV testing in relation to minority ethnic women. They also raised some theoretical and practical implications for HPV testing with regards to cultural and religious

attitudes and practices. The study also demonstrated challenges regarding better, clearer information on HPV testing which is focused on the community and not just targeted at women. The findings possibly suggest different cultural contextual issues are integral to accepting cancer screening and although the study by McCaffery and colleagues (2003) refers to women and HPV screening, their findings, I suggest, can aid in understanding the acceptance or non-acceptance of other screening practices such as breast self-examination or colorectal screening, which for some communities or religious groups is deemed either unacceptable or distasteful thereby hindering preventative healthcare behaviour. Practical approaches which could be taken were not outlined but Abdullahi and colleagues (2009) provided interventions which they purported could be acceptable to Somali women.

In the UK there is a dearth of literature specifically on African women but the study by Abdullahai and colleagues (2009) provided an insight into cultural issues, which, they argued, impacts on healthcare access and knowledge of screening. The researchers investigated the uptake of cervical screening by Somali women in North London. Fifty Somali first generation women were recruited and data were collected through a combination of focus groups and individual in-depth interviews. As with findings from the work of Box, (1998) and Scanlon and Wood, (2005) factors affecting attendance for cancer screening included language, fear, lack of knowledge, fear of the test, male practitioners, embarrassment and fatalism. However an additional concern which Abdullahai and colleagues (2009) added to research knowledge was the issue of female genital mutilation (FGM). The authors suggested the women themselves seemed to indicate they were not embarrassed by having FGM but were uncomfortable about how Western health professionals would

respond to them having had FGM and therefore it became a barrier to having cervical screening. The authors advocate the use of DVD materials, pictorial rather than written images, and like Chui (2004) advocated the involvement of community workers to better inform Somali women of the benefits of cervical screening.

The involvement of health advocates from the community has been a frequent observation (Lanceley and Cox, 2007; Lodge, 2001). Chui (2004), using Participatory Action Research (PAR), drew attention not only to the value of health advocates in supporting BME women in understanding cancer screening to improve their attendance, but also how healthcare professionals' attitudes to rationalise the low uptake of cervical screening by BME women were misplaced.

Chui (2004) utilised Participatory Action Research (PAR) to challenge what she argued was the perpetual use by many authors of the 'deficit' model of methodological and theoretical approaches to research when researching BME women and cervical screening. She points out the 'deficit model' research has a number of faults; it tends to advocate women's lack of information as the reason for the low uptake of cervical screening, it perpetuates flaws in the over-usage of ethnicity terms in research without definition and coupled with how 'language' and 'culture' is then used as a basis for explaining the lack of engagement with the health service by minority ethnic women, leading to victim blaming.

Chui (2004) recruited women based on language as opposed to culture and six language groups were used: African-Caribbean English/Black English speaking; Pakistani and Urdu/Mipuri speaking; Chinese/Cantonese-speaking; Bengali Syhleti

speaking; and Vietnamese, Vietnamese- Cantonese speaking. In addition, she recruited six smear takers. All participants came from across three health districts in North England. Data were collated from focus groups through a three-stage process. The juxtaposed position between the minority ethnic women and the smear takers was striking. The majority of the BME women had never received an explanation about why the smear was being taken nor had the procedure been explained to them. These negative experiences impacted on returning for repeat testing. Health professionals' lack of understanding of cultural norms, coupled with negative attitudes, created an environment in which ethnic minority women found it difficult to engage with health preventative practice involving health professionals. For many of the women smear taking was an opportunistic test undertaken post-natally, thereby leading to misunderstanding about the purpose of the test. The smear takers, however, believed minority ethnic women were not interested in health screening.

The cyclical concept of PAR encouraged self-exploration by the smear takers of their attitudes towards BME women and their perceived lack of engagement with healthcare and led to what Chui (2004) articulated as their willingness to engage in training to improve their understanding of cultural issues and to recruit and utilise community advocates, thereby improving the service. Chui (2004) pointed out that since PAR is action research it is an iterative process and therefore the findings are not static but a continuum of gathering data, interpreting it at each stage, leading to actions being taken. However, her conclusions demonstrated that when an ethnic minority of women are given information and health workers utilise community health advisors, these actions can have a positive impact on attendance for cervical smears. Chui's use of PAR has challenged the deficit model of thinking, identifying

not only causal issues of low uptake of screening but also providing a basis to help support and increase knowledge and awareness between the women and the smear takers to improve uptake.

Breast screening in the UK is a national programme and attendance for mammography is recognised as an important part of preventive cancer care. Acceptance of mammography and hence attendance for screening has arguably been less effective for BME women. Breast cancer has a lower incidence in black women but they have a higher mortality rate in comparison to white British women and understanding any causal factors is an imperative to improving survivorship. Research findings from studies by Ajose-Adeogun and Qureshi (2012), Littlewood and Elias (2000), Pfeffer (2004), Okobia and colleagues (2006), provided some insights into the complexities of socio-cultural, religious, emotional and financial challenges which interplay in decision-making in relation to cancer screening.

A qualitative study in South London to determine the level of understanding and awareness of cancer and cancer screening services in African and African-Caribbeans was conducted by Ajose-Adeogun and Qureshi (2012). Eleven participants were recruited and semi-structured interviews were undertaken. The findings highlighted women were aware of breast screening, a contrary finding to earlier work by Box (1998), and concurred with Thomas and colleagues (2005), but there was limited understanding of signs of cancer, or awareness of common cancers found in black people. Ajose-Adeogun and Qureshi (2012) also drew attention to how culture and religion impacted on health behaviour and beliefs but did not delve into what lay behind those beliefs. The authors also alluded to the

differences between African and African-Caribbean participants in how cancer was perceived, but this was not developed and discussed. This is a strikingly key point seldom explored in literature in understanding what the differences are in response and behaviour in relation to cancer by these two communities. My study draws attention to these issues and how they impact on health-seeking behaviour in relation to cancer care.

Understanding delays in seeking healthcare was the focus of Littlewood and Elias (2000) study which aimed to gain an understanding of the delay of health seeking behaviour by African and African Caribbean women with regards to breast screening. The study was conducted in London and using non-randomised sampling, ten women were recruited and semi-structured interviews were undertaken at diagnosis, at six weeks and three months post-diagnosis. The authors drew comparisons between the risk model of biomedicine to the findings from their study on risks perceived by the women in their study and concluded the importance of recognising how African and African-Caribbean views on risks within their rationale for health-seeking behaviour bore no resemblance to biomedicine risk formulations. This reflected findings from later research by Pfeffer (2004) on candidacy and compliance in accepting breast screening invitation (see p.44). Pfeffer (2004)'s work like Littlewood and Elias's (2000) suggested there needed to be recognition of the cultural complexities and awareness of local taxonomies if healthcare strategies relating to cancer were to be effective.

Liitlewood and Elias (2000) also concluded women's belief about cancer, social stigma, anxiety, which revolved around the fear of receiving a positive result and

exclusion were factors impacting on timely healthcare seeking. Other causes of delayed health-seeking behaviour related to systems failure and some women not believing the symptoms related to cancer. The fear of exclusion was bound up with religion and there appeared to be contradictory elements to this.

The authors identified women had strong religious beliefs, that cancer was a taboo and associated with being contagious, 'unclean' and promiscuous behaviour. However, religion was also a significant support not only in prayer but socialising, being accepted and gaining acceptance to undergo the treatment, as well as being accepted back into the church community after treatment. The significance of belonging to the Church, the authors suggested, was important for identity, positioning and preserving relationships within the church. Therefore, a diagnosis of cancer could disturb this equilibrium and potentially create a sense of being ostracised from the church community because of underlying beliefs some churchgoers may have about cancer. The fear of not being accepted by the church was of almost an equal concern to being disfigured (that is, from mastectomy) as that represented evidence of being in a white world, cancer being seen as a 'white' illness. These are complex issues but whether they were typical of both African and African-Caribbean women is not clearly articulated and presented for this thesis as an avenue to explore.

Available information on breast screening is ineffective if cultural issues which may affect undertaking preventive measures such as breast screening are not addressed. Littlewood and Elias (2000) demonstrated differences in perceptions of risks between African and African-Caribbean women in comparison to beliefs of

healthcare professionals. Scanlon (2004) compared attitudes across wider ethnic groups and illustrated some similarities with Littlewood and Elias (2000) findings, but also suggested in addition to religious aspects, the level of SES of women and experiences of cancer in the country of origin for the BME women played a role in awareness and acceptance of breast-screening services.

Delving into exploring attitudes, knowledge and beliefs about breast cancer amongst women from minority ethnic groups was the focus of Scanlon's (2004) qualitative study which was conducted in London and Sheffield. Seventy-eight women of Asian and Arabic ethnicities and ten white British disadvantaged women were recruited. Data was collated from focus groups and the findings demonstrated similarities between all the women regarding breast cancer which included, lack of knowledge of risk factors, signs and symptoms of breast cancer, pessimism about cancer and beliefs about prevention and cure, barriers to accessing information, personal susceptibility and ideas about fate. It also highlighted that Asian and Arabic women had beliefs shaped by socio-cultural contexts and experience in their countries of origin, which impacted on their behaviour and beliefs about cancer with regard to seeking help and carrying out preventative measures (that is, breast self-examination, attending mammography testing). Fatalistic beliefs were highly prominent in these women; they were convinced nothing can be done about cancer. Based on their experience, the women's view of cancer was that it was always a death sentence and breast screening was not going to be beneficial, hence the low uptake of the service.

Whereas previous studies have been primarily related to knowledge and cultural values which play a part in cancer screening, Pfeffer (2004) took a distinctly different approach. Her focus related to the impact of the invitation letter for screening and responses on receiving it and the uptake of attending for mammography. Her aim was to discover what drove the differences between women accepting their invitation for mammography and others who do not. The author explored women's perceptions of breast cancer and the three approaches to early diagnosis (namely breast self-examination, the NHS Screening Programme and mammography). The study took place in East London and the recruiting of women was based on skin colour, language, social status and faith. The author did not state the total number of women in the study, but provided numbers of either the ethnicity or language group the women represented. The recruited women represented African-Caribbean women, Cantonese, Gujarati, Sylheti, Turkish and Punjabi speaking women, white British and white Jewish women.

Pfeffer (2004) found that candidacy and ethnicity emerged as similar constructs which women used to make claims about their risk of breast cancer and impacted on how they responded to requests for attending breast screening. Underpinning candidacy were issues related to how the information was presented, understanding the significance of the request, and in particular the belief by minority ethnic women that breast cancer was an illness affecting white women. By including white women, the author claims it created the opportunity to develop general themes which applied to all women. For example, compliance in attending for mammography was for some women across all ethnicities affected by social and economic factors such as transport costs and being embarrassed as well as the fear of a diagnosis of breast

cancer. Pfeffer's work adds to the research knowledge in how women discern between accepting the invitation and dealing with the everyday challenges of life.

Breast cancer is a global phenomenon and there are differences in incidence and prevalence rates across the world. Okobia and colleagues (2006) indicated Nigeria had a low prevalence of breast cancer but it has increased significantly with extensive delays in women seeking treatment resulting in higher mortality than among Western Caucasian women. This research is of interest for my thesis as West Africans, particularly Nigerians, are the largest African group in London, therefore the study by Okobia and colleagues (2006) provided an insight into experiences of breast cancer back in their own country. The aim of their study was to evaluate knowledge, attitudes and practices of Nigerian women towards breast cancer. This was a quantitative study involving 1000 women recruited from a random selection using the household population- based census of 1991. Data were collected using an interviewer-administered structured questionnaire which was completed by the participants with community nurses recruited to conduct interviews.

The authors found women had poor knowledge of breast screening, poor understanding of risk factors, signs and symptoms which increased the risk of late presentation all of which the authors correlated with late presentation to the clinician. There was evidence of younger Nigerian women presenting with breast cancer which, the authors suggested, correlated with findings of women in the diaspora of black women presenting younger than Caucasian women with breast cancer. These findings are similar to those of Littlewood and Elias (2000) and correlate with wider

literature on black women presenting with breast cancer, at least twenty years younger than white British women (Bowen and colleagues, 2008).

Okobia and colleagues (2006) found a correlation between women who had higher education and those in professional jobs and better awareness of breast cancer and had greater knowledge given higher scores regarding breast self examination. Participants expressed the importance of attending the doctor for breast complaints. This is of interest as this issue would appear to be in contrast to findings about black women's health-seeking behaviour in the UK from earlier studies conducted in the UK (Box, 1998), Littlewood and Elias (2000). I would suggest this could be related to cultural dissonance as a factor in such differences in behaviour and concerns regarding trust in the healthcare profession. By cultural dissonance I mean there is a potentially higher possibility of African and African-Caribbean women being cared for by a GP who does not share the same cultural norms, values and beliefs as themselves in the UK. Therefore, with regards to concerns with breast symptoms, some African and African-Caribbean women may find it difficult and uncomfortable to discuss such intimate problems with a Western white doctor. It is more likely women in Nigeria are cared for by a healthcare practitioner who shares the same cultural norms and values and therefore the cultural dissonance is less likely. Thus communication and attending to the healthcare practitioner may not be perceived with the same reticence as it is for some African and African-Caribbean women in the UK.

The SES status outlined in the UK studies such as Box (1998), Littlewood and Elias (2000), Scanlon (2004) indicated the BME women in their respective studies were of

low SES and linked that with low level of knowledge regarding screening. Okobia and colleagues (2006) identified that women of lower SES and lower education also had limited knowledge regarding cancer symptoms. It is difficult to draw a correlation between the levels of SES between the participants of Okobia and colleagues (2006) and the participants in the UK studies since with migration commonly migrants undertake employment which categorises them as being in the low SES, but the level of education for some migrants may have them as being in a higher SES in their country of origin. Therefore, SES is a challenging variable if not considered in context with other drivers associated with SES, which include level of education and for BME's experiences of being a migrant and the length of time in the UK. All these interplay with interactions between service user and the health professional.

The representation of black women in breast health research is deficient, a conclusion by Banning (2011) having conducted a review of the literature published between 1994 and 2009. She focussed on exploring black women's perceptions of breast health and factors that influence cancer screening practices and reflected on the paucity of UK data regarding ethnicity and uptake of breast cancer screening, survival and mortality. Banning (2011) identified three main themes from the literature: importance of perception of breast cancer and breast cancer risk, breast cancer screening, impact of spirituality and religious belief on breast health. She ascertained black women held a variety of views and perceptions regarding risk factors, awareness of symptoms, religion and spirituality, and stigma, all of which impacted on attending breast cancer screening services. Banning (2011) concluded that awareness of breast cancer was low amongst black women and many considered breast cancer to be a white woman's illness. The lack of awareness of

how to conduct breast self-examination was alluded to in contrast to findings from Pfeffer's (2004) who inferred women were taught breast self-examination. Not having awareness of how to conduct BSE, coupled with fear, fatalism, pessimism and lack of belief in the effectiveness of treatment were linked to the low uptake of breast cancer screening services by black women. These issues appear to have some relationship with level of education and socio-economic status; generally women from low socio-economic status tended to hold these views.

From limited comparative research with white women, Banning (2011) articulated there were also similarities with white women in low socio-economic groups which would suggest that socio-economic factors impact similarly on both groups of women, a finding also identified in studies by Box (1998), Scanlon (2004), but in contrast to Thomas and colleagues (2009) and Becker and Newsom (2003), who concluded race and ethnicity are more significant than SES. To improve awareness of breast cancer screening, Banning (2011) suggested the need to make related material culturally appropriate, a strategy also suggested by Abdullahi and colleagues (2009), McCaffery and colleagues (2003).

Banning (2011) focussed on Black women and breast health awareness and behaviour in contrast to Karbani and colleagues (2011) who conducted a study on exploring attitudes, knowledge and understanding of breast cancer and preventative measures in South Asian women patients and their partners in West Yorkshire. In-depth interviews of 24 South Asian women diagnosed with breast cancer and 15 significant others was undertaken and like McCaffery and colleagues (2003), the interviews were analysed by a framework analysis matrix-based approach to identify

recurring themes. Their results indicated that most of the women were unaware of cancer, lacked knowledge about the disease and its symptoms and many did not practise breast self examination.

The authors found that cancer was misunderstood and there were cultural ramifications on marriage, a finding also in the work of Box (1998), McCaffery and colleagues, (2003). Perceptions of cancer were based on cultural beliefs, cancer being a taboo subject and seen as a stigma. Cultural beliefs and practices created difficulties with access to breast screening, understanding breast self examination and seeking healthcare support. Spirituality was important as part of the healing process as this provided comfort. The value of spirituality and its meaning in coping with cancer has been alluded to in other studies (Henderson and colleagues, 2003; Koffman and Higginson, 2001; Koffman and colleagues, 2008a). A significant issue raised by the authors and links to the findings of Pfeffer (2004) on candidacy and compliance is the apparent low number of South Asian women with breast cancer being detected through the national breast screening programme. Pfeffer's (2004) research provided some contextual data indicating a partial response to this issue, but Karbani and colleagues (2011) did not explore in their own research any correlation between being in receipt of information for attending breast screening and the low attendance; however, their findings implied a possible disconnect with efforts by the national programme to address the cultural and social factors which impact on undertaking breast screening practices.

Recognising barriers to accessing cancer screening services for breast, cervical and prostate cancer, was also explored by Thomas and colleagues (2005). They

recruited in North London 133 participants who were from African, Caribbean, Gujarati, Greek, Pakistani and Arabic communities and focus groups were organised into ethnic groups to collect the data. In addition, 25 health professionals were recruited and data was also collected from them through focus groups. From the community participants, the results highlighted the general lack of awareness of specific cancers affecting their communities, with the exception of the West African group who recognised breast, prostate and liver cancer. The youngest age group was the most unaware of cancer screening and this is of concern, particularly as it is well documented that mortality from breast cancer is higher in younger black women compared to their white counterparts (Bowen and colleagues, 2008). Access to female clinicians for breast and cervical screening was a particularly important indicator in accessing screening services, a finding in later studies by Karbani and colleagues, (2011). Knowledge of and uptake of screening was poor; however, for those that had attended for screening, how they felt they were treated had an impact as to whether they would consider having repeat tests.

The study also highlighted cultural beliefs and attitudes to cancer. The word 'cancer' was perceived to have some malevolent power; thus the fear of uttering the word by some in these communities makes it difficult to discuss cancer and make cancer prevention strategies effective. The West African group indicated cancer was an important illness but a great deal of taboos surrounded the subject, particularly cervical and uterine cancer. The belief that it was contagious, passed through families, meant there was a fear of being ostracised by the community if it became known someone had cancer.

Thomas and colleagues (2005) found difficulties with language, lack of accessible information, lack of appropriate translated materials, attitudes of GPs and not being taken seriously, as well as cultural attitudes and values differences between ethnic minorities and the health professionals, were barriers to accessing cancer screening services

2.3.1 Summary

There are underpinning threads in the findings of the studies which related to lack of knowledge, fears of diagnosis, fear of attitudes and responses of healthcare professionals, language barriers, the effect of religion and spirituality. Many of these are shared across all ethnic groups, including the white population. However, there remained some areas which warranted further exploration: for example, culture impact on breast self-examination; what is it about the interplay between culture and the individual which frames behaviour towards screening? Religion is a finding in a number of studies, but how it becomes a central factor and what it is about religious activity that gives it a sense of power in individual's lives is not articulated in studies.

Narrative research was not used in the studies which took place in the UK and this thesis, through using dialogic analysis, ventured into an unexplored method which draws on the cultural understanding in the value of storytelling within these communities. In doing so, the narratives which developed assisted in providing new knowledge and different perspectives on some known common challenges for Africans and African-Caribbeans.

2.4 Cancer healthcare: meeting the needs of black and minority ethnic communities

The multicultural demographics of the UK has necessitated rethinking of how to meet the diverse health needs of the black and minority ethnic communities who are becoming an increasingly ageing population. Cancer is progressively a major health concern for minority ethnic groups and research into how health services are accommodating their needs is reviewed.

Information to lay people on cancer is essential for relieving anxiety and providing support. The provision of information needs not only to be accessible, but understandable to the individual. The skill of healthcare professionals to provide information is fundamental and Lanceley and Cox (2007) investigated the information needs of minority ethnic groups and health carers' attitudes and abilities to meet the information needs of those minority ethnic groups. Lanceley and Cox (2007), using both quantitative and qualitative methodologies, aimed at identifying the knowledge level and information needs of black and ethnic minorities with regard to cancer services. They also aimed to highlight the education and support needed by health and social care professionals in East London.

Six patients, four carers and thirty-three health and social care workers were recruited. Quantitative data were collated through a questionnaire and focus groups of cares and patients and semi-structured interviews with health and social care professionals were used to collect qualitative data. Findings from the focus groups indicated a lack of awareness of preventative and support services information and GPs being ineffective, failing to listen to patients and patients feeling discouraged.

The authors indicated an indifference by healthcare professionals in lacking appreciation of how different approaches to meeting informational needs would be required to meet the needs of black and ethnic minorities. Such attitudes, the authors argued, in addition to language barriers, lack of explanation about cancer, its treatment, effects of treatment and inadequate use of or poor access to interpreting services, increased feelings of stress and anxiety for participants. McCaffery and colleagues (2003), Scanlon (2004), Thomas and colleagues (2005) and later research by Abdullahi and colleagues (2009) found similar intransigence opinions creating a challenging position for many BMEs to engage effectively with healthcare cancer services.

The under-representation of black participants in Lanceley and Cox (2007)'s study is again an issue with a number of studies which have black and minority ethnic communities in their title but the participants are predominately South Asians. Such studies rarely explain this lack of representation. This was evident in the literature review conducted by Banning (2011) on breast awareness as it was in the work of Elkan and colleagues (2007) reviewing 25 qualitative studies reporting experiences of cancer service users for minority ethnic communities. The categorised themes the authors established from the review were: communication and communication barriers, which were exacerbated by inadequate or poor translating and interpreting services and service users feeling they were being ignored; lack of awareness of the existence of services; perceived failure of healthcare providers to acknowledge the importance culture and religion plays in the lives of some people from minority ethnic background. Like Lodge (2001) and Szcepura (2005), Elkan and colleagues (2007) discussed the challenge of collating data on cancer epidemiology in different ethnic

groups and the classification of people's ethnicity. They reported that positive initiatives to combat inequalities being developed in cancer services for minority ethnic communities were being observed, but they were patchy and varied in quality and impact. Furthermore, they suggested that some researchers believed the low uptake of a service was interpreted by those researchers as a lack of need for the service. Cultural incompetence from providers was inferred from the findings of the literature, an issue raised in Szcepura (2005) and in Chui's (2004) conclusions. Elkan and colleagues (2007) concluded that there were still significant disparities between black and ethnic minorities and the white population in accessing preventative and adequate timely treatment and that institutional racism is still apparent as suggested also by Box (1998), Chui (2004), Thomas and colleagues (2005).

Elkan and colleagues (2007) recommended that education and training are fundamental in understanding the needs of minority ethnic communities, but fear the use of a 'checklist' approach could lead to tokenism and to the stereotyping of behaviours and attitudes it is meant to prevent. Whilst I agree with this, I would suggest that cultural competence training might aim to address this and aid in individualised care thereby have the potential effect of changing attitudes and benefit and improve care for all patients. Where good practice is in action addressing minority ethnic needs the authors do not stipulate what is 'good' about the practices and whether those practices relate to developments arising from cultural competence training. I would also question the perceived assumption by Elkan and colleagues (2007) that minority ethnic populations who spoke English as their first language reported no communication problems. This I would argue does not equate

with understanding what was said. Did patients feel able to question? What was the doctor-patient dialogue? How was information provided and what was its impact? These issues were not addressed by the researchers but an attempt to answer these questions could be seen in the study by Lodge (2001) who reviewed literature in relation to ethnic minority groups and cancer to ascertain whether cancer healthcare provision is poorer for those groups when compared to the white population.

Lodge (2001) conducted the research between 1993 and 1999 and categorised the results under six sections: incidence of cancer, mortality from cancer, smoking cessation and tobacco chewing, screening for breast and cervical cancers, attitudes towards cancer and cancer care, feedback from people with cancer within minority groups. He highlighted three main predictors of uptake of screening; attitudes and beliefs about screening, perceived benefits of the effectiveness of screening, significance of support from family, friends and the community. These are still current issues identified in later research (Abdullahai and colleagues, 2009; Redman and colleagues, 2008; Scanlon, 2004).

The findings suggested lack of awareness of cancer and cancer symptoms in BME communities and poor ethnic data collection were significant. He pointed to the need for health professionals to develop understanding of BME beliefs, needs, traditions, cultural norms and behaviour in health and illness and for the community to engage in supporting education and training initiatives was important. These are similar findings to earlier work by Box (1998), Littlewood and Elias (2000) and later studies, Karbani and colleagues (2011), with Lanceley and Cox (2007) suggesting that

difficulties still exist with addressing cultural issues which impact on cancer care for minority ethnic communities.

How an individual copes with adversity has both cultural and individual dimensions and Henderson and colleagues (2003) explored how African-American women coped with breast cancer. Six focus groups were held with between ten to twelve women in each group. The authors indicated the research variable was 'coping strategies used by women to adapt to a diagnosis of breast cancer'. The authors found varied coping strategies shared between the women which included prayer, being positive, having positive will-power, receiving support from family and friends and support from black cancer support groups. Prayer combined with spiritual beliefs was a major supportive factor and the authors described spirituality as a reliance on God throughout the women's breast cancer experience. The value of prayer and spirituality was of importance in the findings from Karbani and colleagues (2011), Nanton and Dale (2011). How those support structures were used and what it was about them that aided in coping were not explicitly explored and opened up avenues of exploration for this thesis.

Understanding cultural differences to aid in effective communication is a well known essential criterion for the provision of high quality cancer care. Papadopoulos and Lees (2004) explored cancer and communication using interviews of men representing different ethnic groups. The study took place in North London and six men and their wives were interviewed. The men were African-Caribbean (one Jamaican and one Mauritian), Bangladeshi, Greek-Cypriot, Irish White British. Data from the interviews were combined with biographical and contextual data to

construct case studies. The findings identified similarities and differences of communication which the authors categorised under the headings of health professionals, families and friends, God/Allah. Furthermore, how the men conferred meaning to having cancer was articulated. All men displayed despair and anxiety at the diagnosis regardless of how they were told. These are not surprising emotions and were also found in other studies (Karbani and colleagues, 2011; Nanton and Dale, 2011). The authors suggested what aided in relieving the despair after being informed of their diagnosis was the clinician providing a sense of hope and how that hope was communicated. Religion played a significant part in most of the men's lives except in the case of the white British male who was described as an atheist. The difference in the meaning of cancer portrayed by the men, the authors suggested, is of importance to healthcare professionals in establishing effective communication taking account of cultural sensitivities.

The study was important as it focussed on men, particularly because of its inclusion of BME men as they are the group underrepresented in research. However, the findings based on a single male from a particular ethnic group, cannot be representative of men within that group. Furthermore, what is not addressed is whether religion was a continuum of belief the men held or whether being diagnosed with cancer brought about a resurgence of their religious beliefs.

Evidence from North American studies has demonstrated the high risk African-American men have of developing prostate cancer; however, in the UK the evidence had been anecdotal. This lack of empirical research was addressed by Chinegwundoh and colleagues (2006) who conducted a population-based

quantitative study in North East London to compare risks and present features of prostate cancer between European, African-Caribbean and South Asian men. The sample size was 248 European, 91 African-Caribbean and 20 Asian men who had been diagnosed with prostate cancer between1999 and 2000. The ethnicity of the men was based on data gained from the UK census categories. The authors indicated the study was the first in the UK to demonstrate African-Caribbean men have a three times higher risk of developing prostate cancer in comparison to white and South-Asian men who have the lowest risk. However, it is not clear as to why there is a higher risk and younger presentation of African-Caribbean men. The authors associated their findings with research from the Caribbean with particular reference to Jamaica which has one of the highest incidences of prostate cancer in the world but made no reference as to whether North-East London has a high Jamaican population and how many of the African-Caribbeans originated from Jamaica were in the study.

This study has been valuable in establishing both incidence of prostate cancer and the need for health professionals to recognise such risks in black-Caribbean men, particularly those of Jamaican origin. I would suggest that what these findings also present is the importance of undertaking qualitative research, exploring the wider issues on not only being diagnosed, but the experiences of cancer in relation to prostate cancer and identifying how men cope with such a diagnosis. The work of Nanton and Dale (2011) aimed to address these qualitative issues.

Nanton and Dale's (2011) study focussed on African-Caribbean men living with prostate cancer in Central England (Birmingham) and they investigated African-

Caribbean men's perceptions and experiences of treatment and care for prostate cancer. The authors sought to identify whether ethnicity played a distinctive part in determining that experience. Sixteen first generation African-Caribbean men diagnosed with prostate cancer were the inclusion criteria and data was collected from one-to-one interviews.

As with other studies (Banning, 2011; Koffman and colleagues, 2008a) the authors found that faith was a predominant theme as was family life, which were similar findings to the Henderson and colleagues (2003) study, but the theme of 'work' and its role in men's health and their interactions with healthcare professionals was a new area not addressed in other studies. Other findings were grouped major under themes: presentation and previous knowledge, diagnosis and decision-making, treatment, care and side effects and the final theme was informal support and social care. The findings correlated with other studies of white men with prostate cancer, but the authors argued these themes were compounded by cultural insensitivity and a healthcare system which was unresponsive to BME men's needs. The study further illustrated a social context which hitherto has received scant attention in previous UK health literature, which is the experience of migration of Caribbeans and prior life events which impact on responses and attitudes to illness and healthcare.

2.4.1 Summary

Studies have aimed to address factors which affect the access and utilisation of cancer services. Quantitative studies provided valuable data on differences between and within ethnic groups in the utilisation of health resources and qualitative research has provided some contextual data to enrich such statistical evidence.

However, exploring cultural differences between African and African-Caribbeans has not been addressed. African and African-Caribbean communities are not a homogenous group and differences in experiences, reaction and responses to cancer diagnosis and interactions with health professionals have not been alluded to in other research, but are explored in this thesis.

2.5 Palliative care and BME communities

My study explores the cancer journey and palliative care is an important part of that process. It is an aspect of cancer care in which there has been limited focus on African and African-Caribbeans and the lack of understanding about such services by these communities, coupled with the lack of or hesitancy in being referred to palliative care, increases the misunderstanding and misconceptions faced by both the individual and their family.

Some research has focussed on medical professionals and their role with BME patients needing palliative care. Ascertaining attitudes and beliefs of GPs and hospital consultants and how they affect referral of non-white patients to palliative care services was the focus of Karim and colleagues (2000) research. This study was set against the publication of the report of the National Council for Hospice and Specialist Palliative Care Services 'Opening doors: Improving access to hospice and specialist palliative care services for black and ethnic minority communities' (Gaffin and colleagues, 1996). The study took place in Birmingham which is significant and continues to have a growing black and minority ethnic population.

They reviewed referral data to their hospice over a 17-month period and found an increase in referrals from a previous audit undertaken a decade ago. The authors' assumptions were that the details behind the data were missing with regards to under-utilisation of the service. The authors did not provide statistical data on the ethnic groups of the patients referred to the hospice. Difference in referrals of different ethnic groups would help recognise whether specific targeting of GPs or the need for varied information targeted both the community and GPs with a low referral rate may have been required. Semi-structured interviews of 27 doctors, 12 GPs and 15 hospital consultants were undertaken. Stratified sampling was used to select the GPs, based on how many were single practices (where the practice only had one GP), GP practices which had two or three GPs and practices with four or more GPs.

The authors indicated that all the GPs who took part were white and all those who declined were Asian. In the discussion the authors do not refer back to this issue, but I believe it is of importance and of interest. The reason given for declining, the authors stated, was that the doctor was 'too busy' (Karim and colleagues, 2000, p.473). It is unclear as to whether those doctors were in a single practice with a heavier workload than others, which might give some explanation. Arguably, however, as they had stratified the GPs there were also white GPs with presumably a heavy workload taking part in the study and all the GPs who participated were working within areas where there was a high BME population. Or was there a cultural imperative reflecting the cultural norms and traditions in relation to hospice care? In essence, did the Asian GPs have a particularly negative view of hospices? These are unanswered questions; the authors could have speculated upon or made some inferences regarding this. For example, it may have been possible to review

the records of referrals to gain data on whether the Asian GPs made referrals to other palliative care services. If they had not done so, there could be a need for further research to better understand their lack of engagement with palliative care services.

Their findings highlighted that some GPs believed black and minority ethnic communities looked after their own within an extended family network and that this was a favourable and acceptable practice. Such an assumption, the authors pointed out, did not include any understanding of the changes in BME family structure or that that the burden of care generally fell on women. GPs indicated discomfort in discussing hospice services with BME patients, making the assumption hospices would be seen as unacceptable. Hospitals were seen by doctors as more acceptable to BME patients as they instilled hope by seeming to be giving continuing treatment, whereas hospices related to death. It is difficult to ascertain whether GPs themselves shared the view of hospices being places of death, but by taking such a judgemental stance, GPs clearly could be depriving black and ethnic minority patients of hospice or specialist palliative support.

The findings also indicated collusion between doctors and relatives in not disclosing the diagnosis and referral to a hospice is made difficult when this occurs. This finding was not identified in previous studies reviewed and has implications for relevant engagement and provision of appropriate services. What the researchers do not state is whether this was a behaviour seen across all ethnic groups. Generally, in my experience, such behaviour is not commonly seen in Caribbean families. As the study did not disclose numbers of specific ethnic groups it is not possible to compare

commonalities and differences across them. The need for better timely referral to palliative care and for palliative care services to be more sensitive to culture and religion was paramount and are conclusions drawn by Redman and colleagues following their literature review on ethnicity and palliative care (2008).

Karim and colleagues' (2000) study focused on clinicians and their attitudes regarding hospice services. The researchers recommended that future research involving BME users as well as relatives of minority ethnic community patients should be undertaken. Koffman and Higginson (2001) address this issue in their research. Koffman and Higginson (2001) explored black Caribbean carer satisfaction of end of life care of healthcare provision in primary, community and hospital settings for deceased relatives. Semi-structured interviews of 50 Caribbean relatives and, for comparison, 50 white relatives of deceased patients were also interviewed. The participants were from three South London boroughs and the timeframe for recruitment was based on the deceased having died in the previous twelve months. Participants gave examples of good care in all care settings (primary, hospital and palliative care) but poorer ratings of care provision across all care settings were disproportionately high in black Caribbean participants indicating significant areas of concern.

A number of areas were found by the authors in whom disparity in satisfaction of care was articulated by black Caribbeans which related to: the place where the relative died; more Caribbean patients died in hospital than at home or in a hospice and Caribbeans carers lacked awareness about what hospice services were and how they could be used.

Communication was valued by both ethnic groups but examples of cultural insensitivity and lack of communication were disproportionately identified by the Caribbean relatives in both primary care and hospital settings. General practitioners attitudes were viewed as problematic by black Caribbean carers, leading to feelings of not being believed. In comparison to the white carers, there was a significant difference in black carers feeling they did not have enough time to discuss treatment and the concerns they had. In hospital care criticism from Caribbean cares related to the hospital staff's lacked insensitivity, lack of cultural awareness and inadequate time allowed with loved ones in hospital. The authors pointed out that the issues raised may not be wholly unique to black Caribbeans. They are, however, more profound when measured against the backdrop of wider social and health parameters which leads to disadvantage The authors concluded that access, lack of awareness of services, GP accessibility and availability of information were concerns which warranted rectification to improve equity, in access to palliative care.

A physiological consequence of cancer is pain and the ability to control it is paramount to patients' wellbeing and in relation to palliative care is a fundamental aspect to aid in enabling a comfortable and dignified death. It is a major factor of fear for many patients with cancer and Koffman and colleagues (2008b) explored this phenomenon, wanting to identify meaning attributed to cancer-related pain across African-Caribbean and white patients and to compare coping strategies patients used. The study was conducted in three South-London boroughs and twenty-six black Caribbeans and nineteen white patients were recruited. Framework analysis was used to inductively identify emerging themes from the data and the authors concluded the evidence did not suggest there were any ethnic disparities in the

treatment of pain but the meaning of pain between the ethnic groups did differ. The meanings of pain were grouped as pain as a challenge, pain as an enemy, pain as a test of faith and pain as punishment. The authors identified that although cancer was an illness both groups experienced, more black patients complained of pain. However, the authors indicated that some African-Caribbean patients saw their pain as a redemptive feature and was a mechanism for getting closer to God, suggesting suffering at the end of life was a noble attribute. These findings are a useful extension of thinking about African-Caribbean, illness, religion and spirituality. The researchers indicated that both ethnic groups believed pain to be a symptom to be mastered but African-Caribbeans also saw pain to have one of the two additional meanings: as a test of faith or a means of punishment. Such different experiences of pain in BME patients may mean they have received inadequate treatment or lack access to treatment. The authors' findings have similarities with the findings of Banning (2011), Henderson and colleagues (2003), Littlewood and Elias (2000), Koffman and colleagues (2008a), (Nanton and Dale, 2011) in which religion and spirituality was a fundamental armoury to cope with the challenges of cancer.

McCoubrie and Davies (2006), however, contradicted the value of religion as having any psychological benefits to wellbeing in patients with cancer. A hypothesis McCoubrie and Davies (2006: p380) investigated was that 'patients with cancer with high levels of spirituality and wellbeing are less likely to be anxious and/or depressed'. They studied whether there was a correlation between spirituality and depression in patients with advanced cancer. This study is of particular relevance because of its divergent perspective, since many other studies have pointed to the value of religion and spirituality for these groups. The study was conducted in a

hospice in Bristol and 85 participants were recruited. Of the 85 patients only two were black British and one was a Chinese patient. Anxiety and depression were investigated by the Hospital Depression Scale score and spirituality was analysed by the Spirituality and Religious Beliefs tool. The authors defined the differences between religion (a relationship with a higher power) and spirituality (meaning and purpose in life). The authors presented a negative correlation between spirituality, anxiety and depression in patients with advanced cancer and religious wellbeing had no impact on psychological wellbeing. The authors found that spiritual wellbeing interlinked with psychological wellbeing and suggested patients with high levels of existential/spiritual wellbeing were less likely to be anxious or depressed. The authors explained that when an individual is making sense of their circumstances, finding meaning (referring to high spirituality) has a more positive impact on psychological wellbeing than religious faith. They argued religion could be detrimental to psychological wellbeing because it may present cancer as a punishment. This is an area of interest regarding how the meaning of cancer is interpreted by participants in my study through their personal narratives.

McCoubrie and Davies (2006) made no reference to whether ethnicity or 'race' was relevant to findings and although spirituality was important in previous research findings, Henderson and colleagues (2003), Nanton and Dale (2011) and others also point to the positive benefits of religion within BME communities and therefore this factor, I suggest, should not be ignored. McCourbrie and Davies (2006) argued that religion could pose a negative psychological impact on wellbeing because it may relate to punishment. However, this is in contrast to the findings of Koffman and colleagues (2008b) in which pain was positively seen as a connection to God, even

in those participants who considered pain to be punishment, testifying to it giving them a closer connection to God. These studies highlight a real complex depth of meaning related to God and suffering which can be difficult to untangle or comprehend. McCourbrie and Davies (2006) did not take account of personal historical context that could impact on spirituality and which my thesis explored.

Palliative care is going to be an increasing need by all ethnic groups and Redman and colleagues (2008) undertook a review of the literature to investigate how palliative care addresses ethnicity in provision of care. Redman and colleagues (2008) critically reviewed 31 articles written between 2000 and 2005 which focused on ethnicity and health in relation to palliative care in the UK. They focused on research about ethnicity, race and health that identified commonalities and differences between and within ethnic groups. Papers were categorised under a number of themes: epidemiology of cancer in BME communities in the UK, risks and awareness of screening, palliative and end-of-life care. Their review of articles again highlighted the limited primary research on African and African-Caribbean communities in relation to cancer care.

Twelve articles were reviewed by Redman and colleagues (2008) under the subsection 'epidemiology of cancer in BME communities in the UK; only one paper had any significant focus on African and African-Caribbean populations. Nine papers were reviewed under 'risks and awareness of screening' with only two focussing on black communities. The 'end of life/palliative care' subsection had more papers which addressed this difficult and sensitive subject in relation to African and African-Caribbeans. Nine papers were reviewed and four have a focus on African-Caribbean

communities. This review has established the need for more research on BME communities in relation to cancer and palliative care. In addition, Redman and colleagues (2008) concluded that BMEs should be central to research which is focusing on them. This means greater service user involvement as earlier researchers (Lodge, 2001; Szcepura, 2005) have suggested. These authors called for a greater comprehensive effort to capture ethnicity data which aids in both research development and in identifying innovative creative ways of designing and delivery cancer services.

2.6 Conclusion

What studies have illustrated as a common thread is regardless of methodology and theoretical underpinning by researchers is that lack of explanation, poor communication, lack of information, GPs being barriers to accessing services, the gross lack of ethnic data to enable better intelligence regarding diversity, equality, disparity are evident and still commonplace. The review strengthened the need to have focussed research on African and African-Caribbean populations in relation to cancer and provided the foundation within which to place my thesis. I have explored what is already known and it is apparent there is has been great focus on cancer screening but limited literature addressing other areas of the cancer journey for African and African-Caribbeans. Most studies focused either on screening or on a particular cancer site or generally on ethnicity or palliative care and few included both genders in their research.

This thesis focussed across screening to palliative care illustrating factors narrators talk about issues, how those issues influence the stories they tell and the way in

which the tell those stories, providing new insights about cancer experiences for African and African-Caribbeans. A narrative approach has not been used in UK literature and hence the thesis treaded on uncharted territory. The narrative approach offers the opportunity for a greater exploration of understanding the meanings within the story about cancer experiences. Although each story is a subjective presentation of their experience, as a collective of stories from all the narrators it is possible to draw interpretive meanings, which may not be so easily achieved in other forms of qualitative research and certainly not from quantitative research.

An area of particular interest in relation to my study is what Curtis and Lawson (2000) eloquently described in regards to talk about ill-health. They referred to talk about illness as belonging to either 'public' accounts or 'private' accounts; both are based on expectations and moral pressures of their social and cultural context. They describe private accounts of health discourse as being less censored, expressing understanding and behaviours which may be idiosyncratic to that individual and may fall outside publically acceptable ways of talking about illness. Public accounts of illness on the other hand are censored accounts of experiences which are perceived to be an acceptable way of talking about illness and health in a given culture and context. Curtis and Lawson (2000) observed in the public accounts of illness how participants sought to get consensus of opinion from other group members. This was a useful distinction to be aware of and justifies my approach for conducting in-depth interviews as opposed to focus groups to gain a greater opportunity to harness data in a less censored environment.

Migration as a life event may influence attitudes and experiences with regards to healthcare access, specifically related to cancer care, has received limited exposure in the literature. My thesis has participants who are all born outside the UK, have lived in England for at least six years and hence intercultural interactions related to differences in healthcare experiences between their country of origin and how that affected their relationships with healthcare professionals were explored. Reviewing the valuable research established the background to this thesis, its focus and established the positioning of my research in relation to current studies. The underpinning research and theoretical methodologies for the thesis are addressed in the following chapter.

SECTION TWO: METHODOLOGY AND RESEARCH

PROCESS

CHAPTER 3: NARRATIVE RESEARCH: ILLNESS NARRATIVES

3.0 Introduction

Narrative research is the approach taken to conduct this study, as it offers the opportunity for exploring the richness and nuances of meanings within a story about cancer experiences. Narrative research has transcended the literary world, passing into social sciences, but its journey has been and continues to be complex, due in part to the lack of clarity regarding the epistemological roots and influences which shape narrative analysis and the theoretical approaches taken by narrators. What does seem to be in common agreement between narrative researchers is the importance of temporality, the multiple-voice of the researcher, plot, scene and place (Hall and Powell, 2011; Redwood, 1999).

The words 'narrative' and 'story' are often overlapping terms which were used interchangeably in this thesis. This is in line with the practice of other researchers in this field, and is seen as acceptable (Squire, 2005). However, Gudmundsdottir (2001) appears to attempt to differentiate between story and narrative, suggesting narrative researchers collect stories and write narratives of experiences. This difference in epistemological significance between these terms is reflective of both the interdisciplinary nature of narration and its linguistic origins (Ball, 1997, Currie, 1998; Hall and Powell, 2011). I chose to use both the terms 'narrative' and 'story' because the storyteller is the narrator, providing a narrative account on a sequence of events in plotting out their story and thus using both terms does not, I believe, detract from interpreting the narrator's experiences, emotions and identity.

3.1 Personal narratives

Narratives allowed for exploring not only the story being told, but what lay behind how the story is being told, the sequencing of events and how the sequencing of events unfolds in the story which creates the foundation for interpretation (Squire, 2008). Narrative provides meaning to life, giving connections between events (Ricoeur, 1988) and as Connolly and Clandinin (1990) eloquently stated:

> Humans are storytelling organisms who, individually and collectively, lead storied lives. Thus, the study of narrative is the study of the ways humans experience the world (p.2).

Narratives can serve many functions for both the narrator and for me as the researcher. For the narrator it can aid in positive self-identity and help with emotional adjustment (Pennebaker, 1997, Pennebaker and Segal, 1999). It can be empowering, providing structure and coherence to a chaotic situation, and can be cathartic, as explicitly pointed out by participants in my study. Bell (2002, p.209) supports these points stating:

> Narrative allows researchers to understand experience...lets researchers get at information that people do not consciously know themselves...narrative illuminates the temporal notion of experience, recognising that one's understanding of people and events changes.

Bell's (2002) work resonates with the experience a person has when living with a chronic illness which by its very nature will change over time. How the individual reflects on an illness today and again in the future will be affected by what has happened in the intervening period to shape their experience. Hence this potential for multiple meanings does not mean a story told today, which may be told differently later, was not the 'truth' as the person believed it to be at different times of telling the story.

This thesis focuses on personal experiences presented through oral narratives, with the prime interest being on the content of the narrative. The underpinning tenets which framed the foundation for utilising first person narratives were the descriptions by Bailey (1996), and Manning and Cullum-Swan (1994). They articulated a position regarding the goal of personal narratives which I subscribed to, which was to consider the integrative characteristics of the story and to understand the story from the perspective of the narrator in the context of their lives. 'Experiences' retold during interactions between the narrator and myself were influenced not only by socio-cultural dynamics, but also by how I engaged with the narrator. 'Experience' is therefore a dynamic force', as Scot (1991, p.797) stated:

> Experience is at once already an interpretation and is in need of interpretation. What counts as experience is neither self-evident nor straightforward, it is always contested and always therefore political.

 Essentially, this can mean that different emphasis on what is said, about an experience and to whom the story is being told, can lead to different interpretations about the same event being formed.

Culture as a socially constructed concept, plays a part both in personal experiences and interpretive events and as such, Frank (1995), Riceour (1991), Plummer (1995), and Squire (2008) see culture as an important phenomenon within the context of storytelling. Culture has a degree of longevity and therefore has an impact on the way in which a story is told, how it is constructed, its meaning and the language used. Thus culture is not simply an abstract phenomenon, but an inherent part of the person. It confers both individual and collective identity and provides a platform for interpreting, understanding and negotiating the world around the individual, Aneas and Sansin (2009). This is evidently essential in our understanding of how people

present their story as well as what lies behind the way the story is told. Extrapolating what that means is an important element of personal illness narrative. Each narrator's story in this thesis was a subjective presentation of their experience and as a collection of stories it was possible to identify commonalities between and within the narratives which became important in addressing my understanding of their experiences of cancer.

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3.2 Narrative approach: Dialogic analysis

Dialogic analysis aims to delve into not just what is said and how it is said but also to understand the phenomenon beyond communication itself, which can relate to understanding self, trust, mistrust, new knowledge and relations between groups in society. Conle (2001) argued that as stories are complex and the 'truth' is being constructed, using an analytical framework for narrative research can be indispensable and thus dialogic analysis is the theoretical framework for this thesis. Socio-cultural dynamics between the narrator and listener is not only a fundamental platform for shaping the meaning from dialogue; it is also a basis of dialogic analysis. Dialogic analysis partly has its foundation in symbolic interactionism and to a lesser extent conversational analysis, but this thesis has been influenced by work of Bakhtin (1986) and Riessman (2008). Bakhtin (1986), a key founder in developing dialogic analysis, articulated the engagement between listener and narrator work through finding the 'truth' through dialogue:

> Truth is not born nor is it found inside the head of an individual person, it is born between people collectively searching for truth, in the process of their dialogic interaction (Bakhtin,1984, p.110).

He believed that people are interconnected and influenced by each other and therefore there is always more than one voice to be heard; hence, multivocality can

lead to varying interpretations of the narrative. Words and phrases used have historical meaning, which indicates how dialogic analysis incorporates wider contextual meanings to the interpretation of the narrative. A dialogic process between a teller and listener where the storyteller and questioner jointly participate in conversation is the emphasis in dialogic analysis. Reflexivity is therefore a critical element of dialogic analysis as I bring my own identify to the interaction with the narrator, which had to be considered in the production and interpretation of the narrative data. I return to this issue later in this chapter (section 3.5 p.108).

Riessman (2008) referred to dialogic analysis as a means of examining how talk is interactionally produced as narrative. Dialogic analysis emphasises communication as interactional and is placed within a socio-cultural context and that those interactions can have diverse meanings to the various participants, illustrating that individuals do not live within a vacuum. Dialogic analysis is used because of its broader focus than functional or thematic approaches to interpreting personal narratives. There is more attention on complexities of meanings arising from the narrative and context; the setting and the influences of the researcher are important features to which dialogic analysis pays attention to, as they can influence both dialogue and interpretation of the narrative. Thematic content and narrative structures and functions, as well as the cultural shaping of stories, are not lost in the dialogic approach, but interest shifts to storytelling as a process of co-construction, where the teller and listener create meaning collaboratively (Georgakopoulou, 2004; Riessman, 2005). Bamberg (2006) goes further by also combining context, grammar and content to understand the co-construction of the story. This illustrates the lack of 'clean' separation between the classifications of narrative approaches. Similarly, the

socio-cultural perspective of dialogic analysis can overlap with cultural analysis, highlighting the messiness between narrative approaches.

This thesis has a cultural element to it and initially, in planning and deciding on a theoretical framework, I had considered a pluralist approach of combining methods, an approach that was advocated by Howard (1983) as being useful for having a positive impact on transparency and replicability. However, as there are similarities between the two approaches (cultural and dialogic), I concluded that dialogic analysis enabled focusing on culture, whilst considering the broader issues of the interaction between the storyteller and myself. This is re-affirmed by Riessman (2008) consideration that language and cultural contexts influence construction of narratives in dialogic analysis.

Gerhardt (1990) suggests that interactiontist models have been used to gain a greater understanding of the social basis of the meaning of symptoms and how actors negotiate those to help in either forming identity or legitimising behaviour. This argument adds legitimacy to using an interactionist dialogical theoretical framework for this thesis. In addition, dialogical analysis is well suited to this thesis to understand experiences of black Londoners in relation to cancer services; how they felt they were treated by clinicians who were of different ethnicity and social class to them; how they viewed themselves and their interactions; what enabled them to cope with the diagnosis and treatment and to discover what may be in and behind the story being told. In exploring such experiences, multiple dialogue frameworks are drawn from the narratives in relation to relationships between narrators and healthcare professionals, narrators and other ethnicities and their role in their

perceptions of access, treatment and communication, narrators and other's family background, genders, class backgrounds, ages and migration histories. Narrators will be speaking in all these 'voices', both to me and to implied or imagined other audiences. In addition, by sharing cultural norms, values and traditions with some of the African-Caribbean narrators enabled them to freely speak in Caribbean English, which presented another side of the 'self', through the performance and interpretation of the narrative.

Whilst this kind of research can be characterised as 'insider' research (Robson, (2002), the degree of insiderness assessed, and the relative merits of insider and outsider research are evaluated later in this chapter (section 3.5, pp.108-109) and in Chapter Seven (section 7.6, p.269). However, as a researcher, I do not belong in a fixed position on this continuum, even within the same interview. I may be 'outsider', as a health professional, to narrators telling stories of patienthood; more 'insider' to African Caribbean female than to African Caribbean male participants; 'insider' and 'outsider', in fluid ways, to narrated experiences of racialised and classed prejudice within medical services. A dialogic approach to both interviews and analysis was to harnessing the complexity of interconnections between stories and unravel the multiple layers of meaning from the dialogue, which is supported by Riessman (2008).

In the last two decades there has been a growing interest in how stories counter the dominant story line. Talbot and colleagues (1996) discussed how dominant narratives have the potential effect of constraining personal narratives because dominant narratives set the cultural context in which the narrator tells their story.

They refer to the tension existing between the powers of dominant storylines and the personal narrative which resists them. Counter-narratives provide an alternative to the dominant discourse; it opens up new possibilities of understanding an experience or a particular topic from another perspective (Andrews, et al, 2004). Counter-narratives can be empowering because of their ability to resist and challenge (The Personal Narrative Group, 1989).

We lead storied lives which are shaped by interactions with others, wrapped around by socio-cultural, political constructs, framing identities (Holstein and Gubruim, 2000) and therefore identifying whether counter-narratives exist within the narratives from participants in this study was of interest. Finding counter-narratives within a narrator's story, Andrews (2002) makes several observations; being familiar with the context of the topic; being self-reflective ; and giving consideration as how interviews are conducted as well as how the narrator is telling their story. In addition, Jones (2002) describes how counter-narratives could be identified. Firstly, she argues, the narrator in telling their story may do so knowing it is a counter-narrative. Secondly, the researcher themselves identifies the counter-narrative in the storyline. This approach relies on, on the researcher's knowledge of how participants were recruited, the setting in which interviews took place and any dialogue that occurred prior to the recording. Their relevance is not fully explained by Jones (2002), but what is made clear and is shared by Andrews (2002) is the importance of reflexivity, as this approach is based on the researcher identifying the counter-narrative. Reflexivity is of importance as the researchers' attitudes, presumptions to the topic, can shape the interpretation and the analysis. Thirdly, the term, 'orientation' is discussed and refers the importance placed on a particular topic by both the narrator

and listener. These interpretative approaches by Andrews (2002) and Jones (2002), to unravelling counter-narratives in stories, will be drawn on in this thesis in analysing the data.

A criticism of dialogic analysis is the potential loss of objectivity, with the researcher being part of forming and shaping the narrative. This process can be considered negatively as compromising the reliability and validity of the research. However, the very nature of dialogical analysis is that it addresses a co-constructed dialogue and that subjectivity still occurs in the interpretation of the (re)presentation. Through reflexivity, the researcher outlines their position, biases and theoretical approach to interpreting the dialogue and thereby aims to qualify and clarify the value of the research.

'Subjectivity' in interpretation leads to criticism of narrative research not being scientific .Riessman (2008) presents criteria to address this, namely 'persuasiveness' and 'correspondence'. These criteria relate to the correlations between the data collated, how the analytical theoretical framework marries up with the chosen methodology and whether the interpretation and the meaning the researcher presents persuades the reader. A positive answer to these issues meets standards of validity. This thesis aims to address meeting Riessman's (2008) criteria in using dialogic analysis as the theoretical foundation to explore illness narratives and through combining elements of Hydén's (1997) and Bury's (2001) typologies aids in interpreting the findings from the stories of cancer care experiences.

A further criticism is that the interactional nature of dialogic analysis, in essence creates potential for diverse outcomes and as a consequence there is a lack of replicability. These criticisms are discussed in section 3.4 (p.101).

3.3 Narrative research on Illness

Narrative approaches to illness have grown significantly over the last two decades

> One of our most powerful forms for expressing suffering and experiences related to suffering is the narrative. Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice, (Hydén, 1997, p.49).

Stories are told every day, but when life-changing events such as chronic illness occurs, narratives take on a particular significance to help explain and at times legitimise the effects of illness, side effects of treatment and particular behaviour or physical appearances (Frost and colleagues, 2010; Murray, 2009;Riessman, 2008).

Research on illness narratives has the ability to capture the breadth and depth of understanding how illness affects the socio-cultural paradigm and how individuals construct and reconstruct meaning to their life. Such a perspective provides a greater insight into patient's perspectives on living with a chronic illness than solely taking a biomedical approach. Illness narratives can be strategic interventions in order to assert or project identity and activities in the disability movement, are examples of this aspect of illness narrative (Beresford and colleagues, 2011; Disability Rights Commission, 2002). Furthermore, illness narratives can transform illness from an individual into a collective phenomenon as demonstrated in their role in the establishment of patient support groups (Bury, 2001; Mattingly, 1994; Riessman, 2003).

Bury (2001) alludes to the fact that illness has, for some people, created an opportunity for rediscovering oneself, has generated empowerment and for some patient groups, for example those supporting people with HIV, individuals living with learning disabilities, sickle cell disease, their political movements have helped to change perceptions and policies to some extent (Brown, 2012; Hall, 2004; Robins, 2009; Smith and colleagues, 2006).

Sickness can produce stories, a point most strikingly made by Broyard (1992, p .21):

> Storytelling seems to be a natural reaction to illness. People bleed stories and I've become a blood bank of them.

Illness narratives can be the basis for transforming illness events and constructing a world of illness. They can have a number of actors: the patient, doctors, nurses, therapists, family and friends. Depending on the context, societal and cultural circumstances, the patient sets out their story to suit the audience. In acute illness, the illness is generally limited in time, with quite often an understanding of an end point which provides an end to the story. Chronic illness shares no such certainty as there is no end point and therefore the story may easily follow a linear line which has a beginning, middle and an end. This can therefore create challenges as temporality plays its part in the experience which will change over time with the progressive nature of chronic illnesses.

Cancer is a chronic illness, which generally has an ill-defined end, full of questions such as why, where, what, how and with the individual going through various stages of loss and grieving (Kübler-Ross and Kessler, 2005). Having a cancer diagnosis, which was the case for most of my participants, who had either personally

experienced cancer or cared for someone with cancer, undoubtedly had a major impact on life, and created uncertainty and chaos both personally in terms of emotions and externally, impacting on family, career and relationships. Bury (1982) refers to this is as 'biographical disruption'. Making sense of the effects of cancer diagnosis is what narration enables the storyteller to do and how they present that story is their 'truth' of events and effects. Cancer has the potential to cause bodily changes which can have a significant effect on morbidity and life expectancy. With this in mind, it is not surprising that chronic illness creates what Bury describes as 'biographical disruption' (1982), and cancer undoubtedly does this. As a concept, biographical disruption has been a valuable tool in being both a descriptor and explanatory vehicle in aiding comprehending how people respond and adapt to chronic illness.

Biographical disruption has had its critics from post-modernists such as Fox (1993), and from disability theorists Swain and colleagues (2013). Disability theorists argued limitations are not caused by the disability but by social oppression, created by societal prejudices and restrictive organisational structures (for example, lack of adjustments in the workplace, poor wheelchair access into buildings, poor signage, lack of loop facilities) and hence social disadvantage occurs. In recent years, the disability movement has gained some ground in having legislative changes made; namely, the Disability Discrimination Act (2005) and the Equality Act (2010). These are attempts at increasing equity and equality for people living with a disability to make some positive impact on their daily lives.

However, as Williams (2000) alluded to, and his views concur with the earlier work of Kelly and Field (1996), disability theorists are not wholly representative of people living with a disability since the majority of people develop a disability in adult life and therefore ignore or minimise the significance of pathology and the body is in effect ignoring a fundamental element of what has created the disability and the subsequent chronicity of the illness. Kelly and Field (1996) also suggested the need to look at the physicality of illness, for several sociological reasons; visibility of the illness can impact on interaction and has the potential for limiting social interactions, and because chronicity affects identity reconstruction. Cancer straddles across all the elements Kelly and Field (1996) outlined and as cancer is recognised as a disability, disability theorists risk excluding the impact of the pathology on the quality of life for that individual by only considering the sociological elements of disability.

In addition, Bury (1996) called for relational links on the interactions of the individual living with a disability and their social location. These are significant factors to consider regarding disability, indicating why ignoring the body ignores such individual consequences of living with disability caused by illness. Williams (2000), whilst highlighting the values of biographical disruption as a phenomenological sound concept, raises some issues on its limitations. One such criticism is the adult-centric nature of the concept. It does not, for example, address congenital or genetic conditions which cause a disablement from birth and the adjustments needed to make throughout life. Williams (2000) argues that with such adjustments this is continuity rather than a shifting of the biographical embodiment of the self. I would concur in part with this perspective, but as a child goes through development, adolescence, adulthood, there are different struggles to face in society (intimate

relationships, employment, having a family) and would Williams (2000) view of continuity still hold, or is there a shift of how that person may need to reconstruct their identity?

Another limitation Williams (2000) articulates is the relationship between what he refers to as 'normal crises, class, norms, expectations and biographical disruption'. He suggested a potential class differential in relation to biographical disruption, indicating that it is possibly those individuals who are more privileged feel biographical disruption to a greater extent than those who are socially disadvantaged. For those who are socially disadvantaged, illness is expected, almost anticipated and is another one of life's issues to manage. In this regard, it is not biographical disruption, but, as Williams (2000) suggests, is biographical anticipation associated with age and social context. This leads to the view that biographical disruption has considerations of class, age, gender, ethnicity, which Williams (2000) suggests are under researched. In regards to this thesis, ethnicity plays a major role, not only in focussing on ethnic groups (namely African and African-Caribbeans); ethnicity is also explored in relation to illness, and aims to partially address the imbalance Williams (2000) refers to in the under researching of ethnic communities by specifically focussing on these two communities in relation to cancer.

I believe the concept of biographical disruption remains of value notwithstanding its limitations as it sets up a template from which medical developments, societal influences on illness and identity can be explored and, as Williams (2000) stated,

'the concept of [biological disruption] is a continuing theme in a changing world' (p.62).

Most individuals may have some plan as to how they see their life progressing and cancer can completely turn a person's life upside down. The future is full of doubt and the sense of lost opportunities and mortality becomes a premature focus. Individuals have many different ways in which they respond to hearing the word 'cancer' and being given a cancer diagnosis. The understanding of the illness narrative frameworks of Bury (2001) and Hydén (1997) were instrumental in this thesis for providing a foundation to interpret meaning and understanding from cancer-related narratives. Hydén eloquently outlined the value of using an illness narrative framework in that establishing such a framework:

> 'transforms illness events and constructs a world of illness, reconstructs one's life history in the event of a chronic illness, helps to explain and understand the illness, is a form of strategic interaction in order to assert or project one's identity, transforms illness from an individual into a collective phenomenon (Hydén, 1997, p.55)'

For both practitioners and patients, a storyline locates the threatening illness in an imagined life trajectory (Mattingly, 1994; Riessman, 1993). Meanings of life events are not fixed or constant, but evolve, influenced by subsequent life events and socio-cultural context. The narrator selects certain events and arranges them in such a way as to form a whole, with a beginning, a middle and an end, which provides meaning to them and gives the narrator their 'truth' of the events. How those events are presented is affected by such contextual factors as class, race, age, gender, ethnicity, previous experience with health professionals, cultural attitudes towards

doctors, and the deference that some patients may have towards a doctor are of importance for this thesis to explore.

Personal narratives about illness can raise some challenging questions regarding the identity of self, but they equally provide insight into the cultural and social constructions of illness. Illness narratives can also aid in restructuring an individual's life history in the event of a chronic illness and give focus on being able to explain and understand illness. Illness narratives can be autobiographical or they can be stories from friends and relatives who have cared for someone with an illness.

In the past, patients' stories about medical encounters with doctors had been met with scepticism by the medical fraternity. Armstrong (1984) provided a historical account of what he suggested was a shift in perception by doctors in the interest of patients' stories. Theories presented in the 1970s and 1980s about new interest in the patient's voice in medicine were 'no more than artefacts of these changes in perception' (Armstrong, 1984, p.737). Armstrong was drawing attention to limited changes in doctors' behaviour and attitudes towards seeking to fully understand the patient, to listen and interpret the patient's narrative. Doctors would hear the symptoms the patient would talk about and look for signs which would aid a diagnosis. However, little attention was given to what the illness meant to the patient, how or why the patient explained their symptoms, what impact socio-cultural factors played on the illness and their significance to the patients. Before this time, biomedical research, valuable in its approach to developing new treatments and other technologies, had rarely taken account of the individual and did not address experiences from the patient's perspective. The work of Hurwitz (2000) identified

how some major disasters in medical research which created phenomenal adversarial attitudes towards clinicians, had an effect on increasing the interest in narrative analysis within medicine and turned attention from 'disease' to 'illness'. Frank (1995) and Kleinman (1988) aimed to highlight the importance of the patient's 'voice' in doctor-patient relationships, and Kleinman (1988) in particular advocated that external forces of socio-cultural factors placed importance on the meanings of illness in how the patient talks about their illness. Marshall and O'Keefe (1995) had medical students use 'I' when reflecting on an AIDS patient's story of his diagnosis, which was a powerful tool for enabling students to evaluate themselves and their feelings and to understand how the social, cultural moral parameters of a diagnosis affect the meaning and the language and metaphors used by the patient.

Marshall and O'Keefe (1995) advocated 'listening to' and 'hearing' to what the patient is saying. Much effort has been made in medical education to include first person-narrative into the medical curriculum; however, as Garden (2007) argued it is not without difficulty and challenges. It is evident from Garden (2007) and Marshall and O'Keefe (1995) that incorporating first person-narrative early in medical education has a vital role in understanding how language can have differing interpretations and meanings. For example, Lawson (1998), in her study of black women with breast cancer using narrative analysis, highlighted that risk perceptions of the patient often vary from those of clinicians addressing biomedical risk factors. Women in her study often attributed breast cancer risks to factors such as stress, vigorous exercise, lumpy breasts, higher authority (relating to God) and a sense of inevitability. These were similar findings in later studies Scanlon (2004), Karbani and colleagues (2011). In other words, illness narratives can incorporate and build upon

cultural ideas about the causes of illness and about the illness itself as a way of

transforming the illness into a part of one's own life, something which also makes the

illness part of the shared culture, but which may depart in important ways from

biomedical discourse.

Lawson's (1998) study gives credence to the work of Steiner (2005) and Charon

(2001) who formed the term 'narrative medicine competence':

> The effective practice of medicine requires narrative competence; that is, the
> ability to acknowledge, absorb, interpret, and act on the stories and plights of
> others (p.1997).

She further proposed that physicians can enhance their clinical and emotional

development through retelling clinical stories, which concurs with the pedagogical

approach to medical education described by Marshall and O'Keefe (1995).

Stories can aid in the construction of more positive relationships between practitioner

and patient by the practitioner gaining an understanding of how the illness

experience affects the individual. However, this can only take place if clinicians and

narrative analysts in illness narratives take account of what Shapiro (2011) refers to

as 'narrative humility'. This raises the point that although there is growing interest in

narrative medicine, concerns about the authenticity, reliability and trustworthiness of

personal narratives may delegitimise patients' stories: which could re-affirm

Armstrong's (1994) opinion of clinicians giving a cursory acknowledgment of

patient's stories.

Key illness narrative analysts such as Frank (1995), Bury (2001), Riessman (2003),

and Hydén (1987) have provided an in-depth understanding of the value of illness

narratives. These form a basis for narrative researchers with an interest in illness narrative, for investigating the complexities of living with a chronic illness and the negotiations that individuals make to live with, adapt to their illness, refine their identity and legitimise the effects the chronic illness may cause. Serious illness interrupts lives (Charmaz, 1991) and occasions the 'call for stories' (Frank, 1995, p53). Friends want to know 'what happened', 'how they feel' and stories provide a means for the ill themselves 'to repair the damage that illness has done to the ill person's sense of where she/he is in life, and where he/she may be going'(Frank, 1995, p.55).

Illness narratives enable an understanding of what has happened to an individual and give a picture of the journey of recuperating, which in the case of cancer can either be full recovery or a means to understanding how someone can adjust to morbidity. With potentially life-threatening and life-limiting illnesses such as cancer, oncologists are often asked about time, and they construct narratives of hope for families that blur endings and leave the future ambiguous (Good and colleagues, 1994).

What can transpire between the doctor and patient is a creation of a narrative between them to offer hope and still have some semblance of realism. There is a creation and negotiation of a 'plot' which is time bound within a clinical encounter. This emplotting of a narrative can be couched in terms oncologists use such as 'disease-free survival', as opposed to using the word, 'cure'. Using terms like 'disease free' is a more comfortable cushion for oncologists, as oncologists often only cautiously use the word 'cured' after what can feel like an anti-climax of the

person surviving five years post diagnosis and treatment. This further illustrates how temporality affects doctor-patient interactions in what is said, how much information is provided and how that information is communicated to the patient.

The doctor as the listener, Bruner (1987) points out, frames the story to form a virtual interpretation as to what the narrator means. It is possible, therefore, to surmise that this interaction of words, metaphors, body language between the patient and doctor is not a simple one, but it is crucially important for doctors to understand the patient's narrative if trust and acceptance of treatment and working together towards a shared agreed outcome is to be achieved (Hydén and Brockmeier, 2008).

Frank (1995) suggested in relation to illness narratives, attention to both content and language is essential to gaining greater insight into the narrative being told. Thomas-Maclean (2004), in her study using Frank's (1995) narrative framework, concurs with this view that exploring both the content and structure of stories aids in eliciting greater meaning in qualitative health research. Such an approach can help to give a historical, political, sociological and cultural understanding of health and illness behind the story being told. Therefore, using dialogic analysis for my thesis is an appropriate analytical tool as wider socio-cultural issues to do with ethnicity, race, class, cultural dissonance, migration and its effect on life events, my position and interactions, can be explored within a dialogic framework.

Frank (1995) classifies illness narrative into restitution, chaos and quest types. Restitution narrative is the most common of the three and involves three themes which start with health, followed by illness and looking to return to health. The story

revolves around treatment, tests investigations and results. For a patient with a cancer diagnosis, the restitution narrative can be both helpful and harmful. To know that others have returned to health may be good but it is also seen to be reflective of a Western medicine where the entire emphasis is on diagnosis, treatment and cure. To this end, Frank (1995) argued restitution acts as a social imperative to return to health, and misses out on the subtle nuances of the meaning of illness and its effects. In essence, this narrative could be seen as comparable to and highly compatible with the biomedical model of health.

Chaos narrative is very different and involves a narrative in which life never gets better; the stories reveal "vulnerability and futility' (Frank, 1995 p. 97). Such stories lack a sequence of events and timing. However, there is value in such stories according to Frank (1995), as denying or ignoring such stories means potentially not to understand that individual's particular experiences which are important to them. This can be important, for example, in ethnic groups where wider socio-cultural issues play a significant part in how illness such as cancer is viewed. Some may produce narratives of being out of control because of beliefs in a higher power (God), a sense of inevitability, or a sense of punishment. The powerlessness in such narratives is a real issue which requires clinicians to understand its significance in order to support the patient through their treatment.

Quest narratives may be considered therapeutic but can also be too limiting. Frank (1995, p.135)) states that such stories may show movement through illness as 'too clean' a transformation, too complete'. Providing a 'tidy' picture of an illness may form the basis for a cultural imperative for living with the illness and creating an

assumption that when the treatment has ended, so the narrative has concluded. The difficulty with this in relation to cancer is illustrated by Weingarten (2001), who points out that cancer is a long-term condition which by its very nature means there is no end point to the story as the underlying fear of re-occurrence can be ever present.

Hydén (1997) took an alternative perspective on understanding and interpreting illness narrative and proposed a different typology of illness narratives. Firstly, he refers to Hydén's first type as 'illness *as* narrative'; here the narrator, illness and narrative can be combined into the same person. The illness is expressed in and through a narrative. The narrative plays a central role both in the occurrence of the illness and in shaping the manner in which it impinges on the life of the individual. Hydén (1997) suggested it could be seen that the illness is the narrative. The narrative depicts events that have been experienced and that pose problems for the [1]individual. The narrative is a way of integrating or solving problems. The illness is the story the narrator provides and others (researchers) are re-telling, giving coherence to events. The personal narrative does not only reflect illness experiences, but rather it contributes to the experience of the symptoms.

The illness narrative makes it possible to integrate the symptoms and the consequences into a new whole providing a particular social reality. In cancer, the experience of the diagnosis could form the whole story the participant may want to tell and how that has affected them in either how they now view life and relationships, or by giving them a new context or meaning. This narrative type was seen as likely to be a significant feature in all the narratives in my research.

The second type of illness narrative for Hydén is 'narrative about the illness'. Here, Hydén (1997) argued that the narrative conveys information about the illness which is primarily related to professional talk about illness as opposed to interactions between patient and clinician. This could be where professionals talk to each other in a highly clinical contextual manner about the patient's illness. Hunter (1993), for example, suggested that this kind of illness narrative has a central role to play in medicine as a means of formulating and conveying clinical knowledge. Illness narratives which focus on unusual clinical aspects of illness help to describe illness within the framework of particular stories of illness. Sacks' (1993) views reflect this narrative type, indicating that the emphasis of the illness narrative is on the importance of the illness, with doctors imparting detailed clinical knowledge of the patient. This use of illness narrative is evident in 'Grand Rounds' [1] in which a case study approach is taken to identifying and discussing the causes of the illness and pin-pointing possible treatment interventions.

Such use of illness narratives has its value in advancing medical knowledge. However, as Clarke and Mishler (1992) argue, clinicians should also become experienced in listening to personal narratives from patients in order to make a correct diagnosis and to propose treatment which is acceptable to the patient. Their comments are significantly relevant, especially in relation to minority ethnic communities' experiences of clinician-patient interactions. Not understanding or taking account of cultural issues related to illness behaviour creates tensions within the discourse between doctor and patient as alluded to earlier by Lawson (1998).

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[1] Grand round is aimed at being educational in sharing clinical knowledge with and between health colleagues.

Medicine cannot exist without the patient reliving their story and the clinician must be an avid, active listener as this enables them to provide some scientific order to the story to make a diagnosis but still be able to understand the 'human', 'emotional' consequences of the impact on the illness and treatment. As Whitaker (2007), a physician pointed out, patients (referring to those with a chronic illness) are the experts:

> It is important to truly listen to their [patients] stories, to be completely present in the moment we spend with them fully acknowledging that the larger lives they live outside their illness make them, the experts about their condition (p13).

The third type of illness narrative from Hydén is 'narrative as illness'. This, Hydén argues, is where the narrative or insufficient narrative generates the illness. This narrative is predominately associated with people who have neurological or mental disorders and challenges they face in their ability to develop coherence within a narrative. Similarly, it could also relate to individuals with learning difficulties who are unable to use the medium of narrative to make connections between events and experiences or lack narrative abilities for expressing past and current experiences and events. However, as Brown and colleagues (2009) in their study of adults with Down's syndrome using narrative analysis indicated, having the patience to listen to patients' life stories, meaningful learning for the healthcare professional, can be achieved through careful consideration of how data is to be collated and the analytical approach to be used.

Bury (2001) provided typologies of three classes of illness that are different to those of Frank, but that which I contend complement Hydén's typology. Bury's 'contingent narrative' is a type of story that relates to beliefs and customs which form the basis

of how the narrator views the causes of the onset of symptoms. Such attributes would affect how the narrator feels the symptoms affect them or how others see them. Bury's (1982) earlier work on arthritis highlighted how patients discussed their stories around the onset of arthritis, sometimes in relational terms, linking stress and overwork to the onset of symptoms. He also articulated two other sub-strands to the contingent narrative, namely categorical and spectral. The categorical view is based on the identifiable signs and symptoms of an illness which distinguish between the normal and the pathological state, and where the prognosis is generally clearly evident. This would possibly be reflected in narratives of acute illness which generally has a defined ending. This view tends towards a biomedical approach.

The spectral view pertains primarily to chronic illness and societal plus relational issues have more prominence in chronic illness with the individual having to negotiate daily life activities around their illness. Chronic illness being life-long involves changes the person has to adjust to without necessarily seeing any end. The complexity of not having an end in chronic illness poses a significant dilemma in illness narrative research, since there is not always the completion of a story. Cancer clearly falls into the spectral narrative, as it is filled with uncertainties, and the effects of treatments can be life-changing (for example, infertility, cardiac dysfunction). Bury's (2001) contingent narratives parallel Hydén's type of illness as narratives, in which the illness with its presenting symptoms is the focus of the story. Contingent narratives, particularly on chronic illness, refers to the emotional component of the illness for both the individual and their family, and the establishment of coping mechanism used to address the challenges of living with a chronic illness.

Coping and giving meaning to symptoms and the impact of the illness on daily life form part of this narrative type and an aspect of behaviour in regards to this Bury calls 'normalisation'. According to Bury (2001) people find one of two ways in which to bracket off and minimise the impact of the illness, thereby establishing regaining some control. People may normalise in the sense of keeping their pre-illness lifestyle and identity intact by either maintaining as many pre-illness activities as possible and/or by disguising or minimising symptoms. Another approach of normalisation is that people find ways to incorporate their illness into an altered lifestyle so that normal life is re-designated as containing the illness.

Bury's (2001) second narrative type is moral narratives. This is based on values being a prominent part of the illness narrative. The moral judgement or values placed on the illness by the individual and wider society, which are also bound up with and embedded in culture, reflect how the illness is presented, managed and addressed. Government health promotion messages, for example, can be presented as if to 'blame' the individual for the illness and its consequences. For instance, lung cancer, which is associated with smoking, receives less sympathy than sarcoma (bone cancer), for which there is no known cause and no negative behavioural link, which is therefore considered 'bad luck' to have developed. Society's view on contracting HIV still makes it difficult for patients to reveal their diagnosis because of the feelings of stigma created by negative attitudes related to behaviour such as homosexuality, promiscuity and IV drug abuse. Therefore, women who may have contracted HIV after having been raped would find it challenging to disclose their diagnosis for fear of isolation and rejection (Health Watch, 2004).

There are some similarities on the issue of moral contingency in my study with relevance in behaviour and actions associated with cancer. Chapter Three reviewed literature associated with cancer screening, particularly with gynaecological cancers linked to cultural perception of immoral behaviour, can lead to delays in accessing screening service (McCaffery and colleagues, 2003). A diagnosis of cancer itself is fearful not only because of its fatality, but from being ostracised from the community (Curtis and Lawson, 2000).

Bury (2001) contends there is an evaluative element to moral narratives in which there are links between the personal and the social. The individual takes actions or behaviour in which to justify to society, the existence of an altered identity caused by illness or disease. In doing so it also provides a basis for how the individual begins to cope and give meaning to their illness. Furthermore, a sense of rediscovery of self having dealt with and finding a means of coping with the illness is also part of the framing occurring within moral narratives.

In addressing the final narrative type, Bury (2001) referred to it as 'core narratives'. Placing this in context, how an individual talks about illness is set against the background of cultural, social norms, linguistic repertoire which help shape the personal narratives. These factors can assist in enhancing or restricting how the story is told. The work of Gergen and Gergen, (1983) and Kelly (1992), provides conceptual foundations of core narratives. The work of Kelly (1992) and Gergen and Gergen (1983) captures the core narratives with the terms called heroic, tragic, disembodied, romantic, comic and ironic.

Narratives can have a sequence which has one of these forms running through it, or they can straddle more than one of these terms. Gergen and Gergen (1986) refined these core narrative categories and regressive, progressive and stable core narratives were devised. These concepts offer another perspective in understanding illness narratives. Regressive narratives can represent a sense of fatalism, where the story follows a negative sequence of events, whereas progressive narratives are personal stories in which the sequence of the story is one in which the narrator has positive goals, in the face of ongoing difficult issues with their illness. Stable core narratives have a status quo in which the sequences of events do not show any movement, and this resonates with the narrative illness of Franks (1995). In essence Bury (2001) stated that regardless of narrative form the person adopts, the situation is fluid and they can move between the different types depending on circumstance, situation, context and the intentional outcome of the narrator.

In this thesis, I combined Hydén's' (1997) 'illness as narrative' with Bury's (2001) 'moral and contingent narrative' categories, widening their focus to address the significance of ethnicity in illness experiences. Neither analyst addresses this concept specifically within their frameworks. In sum, I broaden Bury's (2001) ideas of moral and contingent narratives, with Hydén's (1997) Illness as narrative to illustrate how other socially derived constructs, such as ethnicity, can impact on the narrative created. How illness is expressed and discussed is framed within a social, historical and cultural context in which ethnicity is a significant component. Neither Bury's (2001) nor Hydén's (1997) ideologies specifically incorporate ethnicity but their conceptual framework allows for such an adaptation.

Ethnicity can play a significant part in illness narrative and it is of particular relevance when the narrators are from minority ethnic communities. Building ethnicity into the combined adaptation of these illness concepts provided a platform to consider another element which plays a crucial role in healthcare interactions and was relevant for this research. Having combined and adapted these illness theoretical frameworks, appendix threee illustrates the interrelationships I have constructed between Hydén (1997) and Bury (2001), linked to Murray's (2000) perspectives, which provided the foundation for Brown's narrative framework.

There were several reasons for the decision not to use the other categories presented within Bury's (2001) and Hydén's (1997) respective typologies. Firstly, my aim was to explore the experiences of cancer services from the perspective of the participant and therefore the focus is on the individual and the story they tell about cancer. Hence, Hydén's 'narrative about illness' type was less relevant as the narrative focus for this illness type refers primarily to how clinicians talk about illness between and amongst themselves and my research did not include healthcare professionals as a group, thus making this illness narrative type irrelevant to the principle objectives of my research.

'Narrative as illness' was not appropriate for my research since participants had the capacity and capability of talking about their illness and giving it context to their life. Bury's (2001) 'core narratives', the premise of the wider socio-cultural factors which impact on the story, are of relevance to my study but capturing those elements within moral and contingent narratives, incorporating Hydén's illness as narrative, I believe

provides a sound basis on which to develop my illness narrative framework. Furthermore, because of the focus of the thesis, it was anticipated that participants' narratives would straddle Bury's (2001) moral and contingent illness narrative and Hydén's (1997) illness as narrative type. It was therefore seen as valuable to utilise both frameworks to minimise any loss of meanings and support interpretations and to increase the reliability and persuasiveness of the meanings produced from the analysis.

3.4 The challenges of narrative research

Narrative research has its limitations and here I return more generally to some of the problematic areas of this qualitative method. A key area that generates much criticism is subjectivity, will be examined and examples of actions taken to address critics are represented. The importance of reflexivity is addressed in the final section.

3.4.1 Crisis of legitimation

As mentioned earlier, narratives are reconstructions, that is, they cannot be seen as exact replicas of events being described. As such, they are always representations of a lived experience and are subject to change and reinterpretation. Recollection changes over time, evolving to meet the needs of the person doing the recalling and the listener on each occasion. Narratives organise memory, but are not pure memory storage devices (Ellis and Bochner, 2000); they are also social products that are generated by people in the context of specific social, historical and cultural locations.

There are differing views between narrative analysts as to how language is used to express the lived experience by the teller and how it should be considered. Cortazzi (1993) considered that the language participants in their research studies captured the reality of lived experiences; other analysts (Denzin, 1997; Gilbert, 1993) view language as constituting that reality. Still others (Riessman, 1993) believe that people may fabricate some elements of their stories, not so much with intent to deceive but more a desire to make their fiction become realities. These differing perspectives and their relation to recollection have contributed to one particular criticism about narrative research which is about what constitutes 'truth'. Arguably, because the 'truth' of a story is representationally inflected and can alter, it has led to criticisms of a narrative 'crisis of legitimation'.

In response to this challenge, some researchers view the fluidity of the story as involving tensions and movements that allow us to understand the handling of the story and truth claims. In other words, such narrative analysis does not treat narratives as stories that transmit a set of facts about the world and it is not primarily interested in whether stories are 'true' or not. In this account the 'truths' of narrative accounts lie not in their faithful representation of a past world, but in the shifting connections they forge between the past, present and the future. As such, they (Denzin, 1997, Gilbert, 2002) view language as constituting that reality.

I agree with Riessman (1993), that the plausibility of a story is what generates acceptance of the story as it is presented. Furthermore, Andrews (2012) makes a compelling statement about experiences stating 'life experiences are a legitimate source of experience, giving that experience is "truth"'. In reviewing all of the stories

from the narrators in my study, identifying common, consistent threads in those stories aided in unpicking the narrative 'truth' as seen by the narrators. This refers back to Munhall's (1989) view that as individuals we make our own reality but if that reality is shared by many others, this can become 'fact'. Spence (1982, p.31) stated, 'contrasting historical truth with narrative truth is the criterion we use to decide when a certain experience has been captured to our satisfaction'. In other words, narrative research is what Polkinghorne (1988, p176) refers to as 'verisimilitude', or the 'appearance of truth'. In this thesis, by identifying how participants' stories are told, I was able to discover convergence and divergence between the stories which enhanced understanding the narrator's cancer journey.

3.4.2. Crisis of representation

Another criticism of narrative research concerns what has been termed the 'crisis of representation', a concept developed by Marcus and Fischer (1999). It refers to the challenges of human sciences having the ability to effectively describe and capture lived experiences, particularly in written form. Part of the criticism of representation relates to generalisation and broad theoretical principles being produced from empirical data which is interpretative.

Generalisation is difficult with narrative research, as themes that can arise are highly particular and because of the multiple interpretations of meaning that can occur. However, as Squire (2005) points out, narrative offers accessibility and universability. Narrative research does not necessarily require replicability of results as a criterion for its evaluation and Moen (2006) points out that narrative research is a continual interaction with theory and data and hence the stories developed in

narrative research are told and interpreted within a theoretical framework, illustrating the continual steps narrative researchers take to present valid, trustworthy data.

In addition, Linde (1993) suggested one perspective on how the data is presented could limit the 'crisis of representation'. The placing of words, pauses and other paralinguistic elements within the written form of the transcript within the context of the background to the interview enables some additional degree of representation of the narrator by the researcher. This makes use of what Linde (1993) refers to as coherence systems to aid interpretation and lessen the crisis of representation. Linde (1993, p164) defines coherence systems as 'systems which claim to provide means of understanding, evaluating and constructing accounts of experiences'. The underlying tenet here is a link with shared beliefs and cultural understandings between individuals from the same communities. Therefore, in this thesis the researcher considers Linde's (1993) concept of coherence systems as a platform for supporting the reliability of the data presented by the participants in my research. They share with me some cultural context, have a shared socio-historical past and, in some cases, have a shared socio-political past within Western society.

To capture these parameters within my analysis of the narratives, I incorporated Murray's (2000) four levels of analysis as the foundation for discussing the findings, to provide a discussion of the analysis of the data. Murray's (2000) four levels are the personal, interpersonal, positional and socio-political. He stressed the importance of integrating these levels in analysing narratives to harness potentially more detailed understanding and meaning from narratives.

Murray (2000) points out that within the personal level stories told by the person who is ill, narrative has a personal function, meaning it provides a basis for the person to take control, which share similarities with Bury's (2001) and Hydén's(1997) work on illness narratives. Personal stories (Murray, 2000) can be therapeutic and can aid in the reconstruction of the self. Murray (2000) articulates the process of telling, offers the narrator some control over what is told and the sequencing of events to tell the story. The interpersonal level refers to the context in which the story is told, which has an effect on the narrative that is then produced. The narrative produced is constructed by the narrator and the listener. The positional level points to the difference in positions between the questioner and the narrator. In relation to illness narratives, the person being interviewed is ill and the researcher most often is healthy and therefore the narrator presents their story in a way to justify their position of being ill. In addition, being healthy can create a position of power for the researcher which has to be addressed to create the opportunity for the teller to feel comfortable with their position.

Addressing the socio-political level involves recognising that narrative is influenced by wider contextual factors. Murray (2000) contends that incorporating all these levels of analysis provides the researcher with a greater grasp of the broad range of factors which play their part in how the story is told and understood and therefore encourages more meaningful interpretation of the data. The underpinning premises Murray (2000) sets out for the four levels of analysis are congruent with the dialogic approach taken in this thesis hence their use as the basis for discussing the findings in Chapter Seven. The discussion of the findings will be reflective of the levels, attempting to present an integrated approach to the discussion.

3.4.3 The issues of objectivity, replicability and generalisability in narrative research

The interactive element of the researcher's role has led to criticism of a lack of objectivity and replicability in narrative research, as mentioned earlier (pp) and as a result, narrative research, much like other qualitative research has been regarded as 'soft', lacking the ability to be generalised. This in particular is an argument made by those in natural sciences and quantitative social research. However, Riessman (1993, p.70) reminds us that 'science has been advanced, as in the case of Piaget and his children, by the close study of a small number of cases and that there is a long tradition in science of building inference from cases'.

Atkinson (2009), in his criticism of narrative research being 'soft', has also criticised the use of narratives as being too reductionist of social phenomena. He purported that this mode of analysis through which the social is reduced to the personal and social action is (mis) represented as 'experience' and social identities are reduced to 'voice'. I consider this limited contextual view of narrative research misses the understanding that narrative can be a form with many strands of representation, referencing many aspects of experiences. Even when focussed on a particular point in a time of a person's life, the story is reflective of how that person feels more broadly and the wider impact the illness may have had. Narration is only as self-limiting as the participant wishes to make it, and that possible self-limiting does not make it any less important. Narratives are not about mirroring the past as Riessman (2008) pointed out, but refracting it.

Depending on the position and motives of the person retelling the story, the particular political contexts will always influence how they represent the narrators' stories. Shapiro (2011) argued neither personal nor third person narratives are without challenges in regard to reliability nor authenticity and therefore as a researcher, taking an approach which pays humble attention to the story is important.

The story is what the patient presents at that time and as researchers we need to live with a degree of unpredictability and ambiguity. The story is the narrator's story and in the case of chronic illness the situation is never static and therefore the story may well change. That does not necessarily make the story any less authentic, since what was said and why, reflected the contextual situation at the time. That is not to say the narrative is not viewed critically, but such criticism is done within the context of compassion and humility, and with awareness that the story being told can have many different meanings and realities for the patient.

There are challenges in the areas of rigour, in narrative analysis getting plausibility and validity. Attempts to address these areas are through credibility, transferability and dependability (Lincoln and Gubam, 1985). Credibility needs to be demonstrated by multiple analyses of representations to illustrate the robustness of arriving at a particular interpretation of events. In addition, to build that foundation of credibility and validity of the analysis, my position as the researcher should be as transparent as possible. With regards to this research, I needed to declare not only my position and role and how my values, norms, culture, beliefs, race and gender may influence analysis and the co-construction of the narratives. I also needed to decide how to

present myself within the analysis. I explore these issues in the next section and Chapter Four (section 4.6, p.137) discusses the positionality of the researcher.

On the issue of subjectivity, Frost and colleagues (2010) consider the question as to how the researcher decides to refer to themselves in their study. Should it be in the first person or third person? I faced this as one of the challenges to consider – how to present myself in this thesis. It was of particular importance in relation to reflexivity. Writing in the third person offered me the position of presenting with objectivity. However, on reflection, considering the chosen theoretical methodology as dialogical analysis for this thesis and how it involves both the narrator and the researcher co-constructing meanings collaboratively, writing in the first person was the approach taken. I played a part in the shaping of the narratives and therefore writing in the first person is appropriate, and a way to acknowledge this contribution.

3.5 Reflexivity in the context of narrative research

As mentioned earlier (section 3.2 p. 75) in dialogic analysis, the researcher is actively engaged in the framing of the narrative, bringing their own biases and identity into the interaction with the narrator. This ultimately means the written report for which I am accountable, is a narrative created by me, generated from the narratives of others. Bakhtin (1986) argued the narrative researcher needs to work with several voices: the theoretical framework which provides the concepts of tools for interpretation and a reflexive voice. This illustrates the importance of me acknowledging the interactive role I played in the dialogue in creating the narrative.

As the researcher, I was acutely conscious of what the focus of the research was and hence what areas I wished to address, but the lead always came from the narrator in terms of how they respond and in what they say. In fact, the narrator almost begins the process of interpretation by deciding what to select to talk about from their social situation. Therefore the analysis of the intended and unintended utterances from the narrator was always going to be being interpretive and I needed to be comfortable with some degree of ambiguity and be able to reach interpretive conclusions.

Crucial to this position is the need for me to be transparent about my assumptions and biases and the position I took on the research topic, which I allude to here and in Chapter Four, section 4.6 (p.138). I am both a nurse and a health academic, with specialist knowledge in cancer. I am a female of Caribbean origin and therefore I share some of the cultural perspectives, values and norms some of the participants in the study. It would not be difficult to share many of their emotions and to understand their challenges which could impact on the co-construction of the story.

My background and the sharing of cultural norms with some of the participants warranted consideration of the 'insider' position I have. I needed to consider how much I shared with them and whether I shared more than I think I did. After all, I was born and educated in the UK not in the Caribbean and that difference could have a bearing on how much I really culturally shared in terms of islander experiences. Their earlier experiences of childhood living in the Caribbean gave them completely different life experiences to my own, in ways I would not be able to connect to. All participants were used to being a majority in their country of origin; I was always

used to being a minority ethnic in the UK. Their migration to the UK, presented a minefield of changes in style of living, relationships with the host community, the stress of migration and racism. Migration was not an issue for me and growing up in the UK meant I experienced and reacted to racism differently. Andrews (2007) account of the insider/outsider position of her work resonated with my perspective on the positions I held with the participants and meant I was able to see both the challenges they faced as well as articulate challenges of the healthcare professionals. Cancer experiences for African and African-Caribbean Londoners should not, I believe, be problematic considering that London is the most diverse city in England as demonstrated in Chapter Two. However, I believe this may not be the case and I wanted to discover whether my beliefs are shared by learning from the stories of the participants.

3.6 Conclusion

Narrative research methodology has become of immense interest in social sciences and is growing within medicine as a means of capturing a greater in-depth understanding of patient experiences and interactions with healthcare professionals. Attempts to classify narrative research and narrative analysis are complicated, and their inter-relationships make them difficult to grasp. The epistemological approach of the researcher as well as their discipline tends to be the prime impetus as to the approach taken in narrative research. Illness narratives, particularly those focussed on chronic illness, have become increasingly important in harnessing understanding of how illness and disability impacts on the identity, the reconstruction of that identity caused by the illness, how people cope with suffering, and the socio-cultural manifestations of illness on chronicity.

Generally there is some linearity to the life cycle, with expected changes in life that are accepted as the norm, although certain events of illness can prematurely disrupt the 'normalcy' of that cycle (for example, early menopause, premature greying). Freeman (2000) presents a compelling view on the notion of linearity when referring to ageing and how societal expectations of ageing impact on a life story, what he refers to as 'narrative foreclosure, the premature conviction that one's life story has effectively ended' (p.83). Cultural lines, which Freeman (2000) refers to, can play an important part in how elders within society are viewed and valued and therefore how their narratives are shaped and valued by the elderly as well as society. Aging in those cultures, in which the elderly are held in high regard and respected for their wisdom, may not be perceived negatively by the individual. In Western cultures, where imagery of youth, beauty and energy are important attributes, if individuals internalise such views they may restrict their own narrative expression, believing they have nothing to offer as an elder.

In considering Freeman's (2000) perspective on life linearity and the cultural context in relation to narrative foreclosure, such a view could be played out, when an unexpected potentially life-threatening event occurs, such as cancer. This is an illness which can occur at any age and the disruption to one's life and the emotional, social and psychological turmoil it creates can lead to the examination of self-identity, self-worth and how an individual sees the world, as well as how they perceive the world sees them as a person with cancer. All this happens alongside the actual and potential effects of the condition, both visible and invisible

Criticisms of the narrative approach have focussed on lack of reliability, problems with validity and trustworthiness. Narrative analysts have provided examples of how such criticisms can be addressed in narrative research and the research process adopted for this study has utilised some of those strategies, which are depicted in Chapter Four. This thesis aims to have wider methodological relevance for BME health research, because of its narrative focus as well as substantive relevance for BME cancer service research and provision.

Embedding ethnicity as a construct within the adapted typologies of Bury and Hydén attempted to demonstrate both the flexibility of how the typologies can be adapted but to also provide an awareness of the need to adapt such typologies in light of societal changes to effectively relate illness narratives of minorities within a host society to fully appreciate their illness narratives.

CHAPTER FOUR: THE RESEARCH PROCESS

4.0 Introduction

As discussed in Chapter One (section 1.3, p.10), culture and ethnicity play a major role in access, interrelationships between the patient and healthcare professional, and patient satisfaction of their experiences with encounters with healthcare provision related to cancer. This chapter describes the research process undertaken for the study of 'African and African-Caribbean Londoners' experiences of cancer services'. I will address issues regarding ethical approval, steps taken to recruit participants, data collection and analysis are detailed and positionality of the researcher is discussed.

4.1 The Research Questions

The research questions and aims are revisited to contextualise the research process. The following questions framed the focus of the research study:

- What affected the research participants' experiences of cancer services?

- How did culture, ethnicity and societal constructs influence the experiences?

- How did culture ethnicity and societal constructs influence the stories participants told and the way they told them?

- What were good and bad practices which affected participants' experiences?

- What is the value of narrative approach in research related to cancer focussed on African and African Caribbeans?

In addition, within these questions existed sub-categories, which reflected:

- Reactions to the diagnosis of cancer

- The impact of the diagnosis on relationships with family, friends, their communities

- Coping strategies adopted to manage the effects of treatment and long-term consequences of cancer and the treatment

The aims being to explore:

- The experiences of cancer services from the perspectives of African and African-Caribbean Londoners and;

- Whether narrative research is a valuable research tool for these communities around these issues.

4.2 Narrative Research and Ethics

'There is simply no good general set of rules or guidelines that ensure moral behaviour with narrations about other peoples lives.' (Josselson, 2007, p.538).

Previous to Josselson's (2007) writing, Ellis (2004,p.5) stated, "there are no definitive or universal principles that can tell you precisely what to do in every situation or relationship you encounter, other than the vague and generic term 'do no harm'".

Ethics, Frank (2002) suggested, are complex and challenging in narrative research. The researcher has to navigate between the relationship formed with the participant and the need to meet the academic and professional demands of scholarly activity. Josselson (2007) concurred with this view, as I do, and I will explain later in this chapter my experience of gaining ethical approval for this thesis.

Frank (2002) articulated the ethical tensions narrative researchers face and viewed morality and ethics as being interlinked, stating that the issue of morals is a risk taken by the participant. This would infer that the participant takes the risk of not knowing how the researcher will interpret their story; will the researcher share the

same meaning as the participant? To this end, Kuhse and Singer (1998) suggested that the researcher's ethics must therefore be to act with care and compassion, which are essential in underpinning morality. This does not mean, as Franks (2002) indicated, that researchers must have or need to share the same morality as the participant. He suggested that 'there are levels of recognition, and it is possible to recognise the storyteller's moral impulse to make life narratable, even while rejecting the specific morality of the content' (p.115). The point Franks (2002) makes about risk also leads to concerns for narrative researchers in how to maintain the anonymity of the participants, whilst striving to produce an authentic and credible interpretation which adds value to the field of narrative research.

Smythe and Murray (2000) contend that the traditional regulative processes of research ethics are inadequate for narrative research. Their position is based on the premise that narrative research by its very nature incorporates 'multiplicity of meaning' and there is therefore an issue of 'narrative ownership'. Narrative research can be inductive and is interpretative; being definitive about intended outcomes from the research is not always possible. This is particularly the case during personal narratives, since the data is co-constructed between the narrator and the researcher and meanings can be interpreted differently between them.

Bond, (2002) infers that researchers should live with uncertainty suggesting by taking such a position recognises the limits of ethical principles and reasoning, particularly in relation to narrative research. Josselson (2007) concurs with Smythe and Murray (2000), implying that traditional research ethics processes do not allow for or are unable to address the inductive nature of narrative research, which is a

significant feature of narrative research. Researchers may need to modify questions or approaches based on strategic changes which would come from data acquired during the relationship between the researcher and the participant. Similarly, Smythe and Murray (2000) suggested during the analysis of the data, drawing interpretations from the data may unravel issues which may impact on the direction of the study. In the case of this thesis, amendments were made to information for the flyer following the first two interviews and this is discussed later in section 4.4.

The context within which the story is being told can assist with what Ellis (2007) refers to as 'relational ethics'. I concur with this approach on narrative ethics since narratives (particularly in relation to my thesis) are being told and shaped within a social, political and cultural landscape which is continually changing, are being redefined and interplay with the relatively movable structures of race, gender, class and ethnicity. Therefore, within this overarching premise, the narrator is not static or fixed because almost everything is relational. In addition, Josselson (2007), taking account of Ellis's (2007) concept, 'relational ethics', argued that it is the skill of the researcher in determining how trusting, relaxed and confident the participant feels during the interview which will have a bearing on the level of self-disclosure and will create relational circumstances. That is, the relational circumstances affect the level of self-disclosure the participant is prepared to give the researcher. Thus, self-exposure the participant provides is some recognition of the trust the participant has developed towards the interviewer.

Although the participant is the 'expert' they are likely to see the researcher as having power and, therefore, it is important the researcher addresses this in order to enable

and encourage the participant to feel and believe their story is of value. There will always be a differential of power between the researcher and the interviewee. In my case, although I am black like the participants, there were socio-economic differences between myself and some of the participants which could have added to the power imbalance between me and some of the narrators. I am an academic, a researcher and of middle-class status and some but not all of these factors were shared by the participants. I have not had cancer but have cared for loved ones with the illness and therefore I might have shared some of the challenges the carers in my study had faced. However, being more familiar with health service structures and organisation I was in a more influential position than the male carers, but in a similar position to the female carer who was herself a nurse.

Horner (2002) and Pezalla, et. al (2012) describe how requirements of self-reflexivity, multi-vocality and research collaboration affect the creation of the narrative. In understanding this issue, I aimed to lessen the imbalance of the relationship with regards to power relations by introducing myself to those who did not know me personally, simply by name and my reasons for undertaking the research. For those participants who knew me, clarifying roles (researcher-participant) was undertaken. Participants chose the venue for the interview, and, when requested by the participant, there were 'breaks' in the interview, usually for refreshments. Accepting their hospitality and being questioned about the study were important to the participants and was an indication of what I recognised as their power base.

All participants were given the participant information sheet two days before the interview and were provided with the opportunity to ask questions about the research, prior to signing the consent form. However, the very nature of narrative research means it is difficult to know what exactly will unfold and therefore it is unclear what data will be provided (Riessman, 2005). Josselson (2007) remarks on this further by pointing out the difficulty of consenting to an unforeseen outcome. Ethics within narrative research therefore sits within a context of implicit trust which builds between the participant and the interviewer rather than just on the fact that the information provided will be respected. This resonates with the term used by Adams (2008), 'narrative privilege', which reminded me that a great deal of trust is being given by the narrator to me as the researcher, a point which is central to narrative ethics. On this basis, earlier work on ethics by Gilligan (1982) provided a basis for such a position by articulating the view of consenting as a relational process in which ethics of care rather than rights is the approach to take.

Narrative privilege also provides a basis to understand who might be hurt or silent in the telling of the narratives and this was a framework to hold as of central value in this thesis. Taking note of the notion of narrative privilege was of importance to this thesis for a number of reasons; my research was on a sensitive topic, opening up memories of past events on a life-threatening and potentially life-shortening illness, which participants could have found emotionally demanding. Hence, for me recognising the need for sensitive questioning was continually uppermost in my mind in the approach I took with each participant. I gauged responses to ascertain reactions of participants to my questioning to judge the impact they may have had to inform further my approach to our continued dialogue. In addition, knowing I was in a

privileged position to listen to the stories of African and African-Caribbean participants who are under researched communities in regards to cancer care, the study not only gave them an opportunity in having their story told, but was of significance in learning about and from participants about their experiences.

By undertaking in-depth interviews I gave particular attention to each participant which enabled hearing from participants' who may have been less confident in speaking out if the data were collected from a focus group. Furthermore, as the study by Curtis and Lawson (2000) demonstrated, there can be a distinct difference in regards to 'private' and 'public' discourse when related to health by African and African-Caribbean communities. Thus, in-depth interviews offered a greater opportunity to gain detailed meaningful data on such a complex and sensitive subject.

4.2.1 Ethical approval for the thesis

The difficult and challenging experience I had of gaining ethical approval reflected the concerns by narrators such as Smythe and Murray (2000) in relation to traditional research ethics and its struggle with narrative research. Ethical approval from the University of West London (UWL) (formerly named Thames Valley University) Research Ethics Committee was granted in 2009, but there was a delay in the continuance of the study due to uncertainty of whether the research also required Local Research Ethics Committee (LREC) approval. Part of the UWL Research Ethics Committee recommendation was to seek clarity on this point (see appendix four). The Chair of the UWL Research Ethics Committee sought advice from two LREC Chairs. Their decision was ambiguous, with one LREC Chair suggesting

LREC is not required, and the other believing the research should be reviewed by an LREC. It was decided that an Integrated Research Application System (IRAS) application should be completed and submitted. Following submission of the IRAS application I was invited to an interview at the Royal Free and Whittington NHS LREC committee on7[th] September 2009. A supportive discussion took place with the panellists and their recommendations were:

- Use the NHS Participant Information Sheet and not UWL format

- Indicate the study would also be looking at good as well as poor practice

The second recommendation provided another dimension to explore with participants as that was not an original explicit focus of the study. This was a relevant additional criterion, given that reviewing literature there offered little mention of what were good practices and where they were mentioned; no elaboration on what was 'good' about the practices was presented. See appendix five for the approval letter.

4.3 Recruitment of participants

Recruiting what is considered the 'right' number of participants to a study is a troubling issue in qualitative in-depth interviewing. A review of expert researchers in qualitative research by Baker and Edwards (2012) on the vexing question 'How many qualitative interviews are enough?' the response from all the participants was 'it depends' (p.42). This was qualified by the reviewers pointing out that the number of participants required depended upon:

> the epistemological and methodological questions about the nature and purpose of the research and practical issues to take account include level of the degree, time available, institutional requirements (Baker and Edwards, p.42).

Relating these conclusions to this thesis supports my decision, not only for the technique used for sampling, but also the sample size. The epistemological stand of this thesis was to learn about and understand meanings of experiences of cancer services in the narratives of black Londoners and to explore the value of narrative research in relation to cancer and the black community.

The approach taken to recruit participants for the study was a combination of convenience and judgement sampling (Fossey and colleagues; 2002, Marshall, 1996). Using this form of sampling also offered the opportunity for snowballing, which was constructive in identifying other participants who met the criteria for the study which were:

- Individuals who had experienced cancer screening services;

  and/or

- Individuals who had previously experienced cancer treatment;

  and/or

- Individuals who were carers of a family member with cancer;

- Individuals of African or African-Caribbean origin who considered their ethnicity to be black African and black Caribbean

- Individuals who live in London.

Furthermore, snowballing enabled me to reach participants who were less likely to respond to adverts such as the flyer and gaining personal recommendation through contacts, provided participants of some assurance as to my credibility and the considered value of their participation. This recruitment approach was appropriate for this thesis: it has practical value in terms of time required to gather the data and access to the required participants, and limited funding was required. Criticisms of

convenience/judgement sampling have generally focused on difficulties with under-representation (of particular groups), small sample size and the challenge of generalisation. However, convenience/judgement sampling is an acceptable sampling process for narrative research as Martin (1996) purports that a small sample size in qualitative research is valuable for in-depth interviewing and analysis.

Participants were recruited from a number of sources which included advertising through flyers which were distributed in three churches in South, North and East London, known for their large congregations, two London universities and two African-Caribbean elders support groups. See appendix six for a copy of the flyer. Referrals from personal contacts formed the second source of recruitment which was charities; (Black Cancer Care, Patients, Voices and health colleagues). In total, twelve participants were recruited, comprising nine women and three men. The larger female group inevitably created some imbalance to the data; however, what became evident were some important commonalities of experiences which transcended gender and formed valuable aspects of the narrative data. Seven participants stated their ethnicity as being Caribbean and five indicated their ethnicity as African. Eight participants were recruited through personal contacts, three participants responded to the flyer from the churches and another participant who responded to the flyer came from one of the elders support group.

The participants came from the four geographical areas of London (North, South, East and West) and all participants had been living in London for over five years. The length of time living in London I regarded as important as it suggested a level of stability, some familiarisation with the healthcare system in UK and being resident

meant that the individual had the right of access to treatment and services, which would not be true for instance of asylum seekers or undocumented migrants.

4.4 Data collection

In-depth interviews were conducted and audio recorded with participants' consent. According to Atkinson (1998), interviews for personal narratives can be constructivist or naturalist in focus. This thesis took a naturalistic approach to interviewing which refers to the interaction between me and the narrator in naturalistic settings in which the interview has limited structure in order to have a dialogue which has a sense of normalcy. Furthermore, such an approach allows for interpretation of understanding the participants' experiences and exploring the meaning of those experiences and actions the participants make.

After conducting two interviews, minor changes were made to the information on the flyer for recruiting participants. This was due to the recruitment of a participant through a colleague. The participant was referred by a white colleague, when I had informed her of my study and the participants I wanted to recruit were to be of African and African-Caribbean descent. I discovered the participant was a male Kenyan Asian. It was of interest to me that my colleague made no distinction on ethnicity when she suggested the participant. This might be reflected in the fact the participant classified himself as a Kenyan. He saw himself as an African. This raised some interesting considerations regarding ethnicity and identity as explored in Chapter One, section 1.3 (p.10). This could have been an issue for the study if participants of other ethnicities had volunteered; African Asian, Arab, for instance. The outcome led to me being more specific in the information used for the flyer and I

tightened up the criteria for inclusion in the study. This reflected the views made by Smythe and Murray (2000) regarding the inductive nature of narrative research and the recognition that changes along the research process may become necessary through engagement with participants. This participant's cultural background as African was emphasised by the fact he did not have any South Asian links; however, over 90% of Asians in London have such an association with the Indian sub-continent. In addition, this participant's data was an interesting contrast to the rest of the sample as his narrative alluded to some fundamental issues on race, prejudice, gender, class, inter-racialism which not only enriched the study, but generated potential areas of interest for future research. In particular, inter-racialism specific to the socio-cultural context of this thesis by, being an Asian widower of a white Irish woman, in which Asian and white ethnicities issues were played out throughout the narrative. This potentially led to instructive commonalities and differences with the rest of the sample.

In-depth interviews as opposed to focus groups were the preferred choice of data collection for a number of reasons. Firstly, interviews allow the participant to tell their story with generally minimal interruptions from me. Secondly, the interviews provided the potential for a rich source of information which arguably can be lost with more traditional forms of qualitative research due to focusing solely on specific areas. Mishler (1986) put this point into context when he discussed the suppression of the narrative with other mainstream traditional forms of qualitative research, such as focus groups, in which the 'person' may be lost. This is a point of interest as the loss of the 'person' in focus groups, I suggest, can occur for several reasons. Firstly, in focus groups, it is possible that certain characters may be dominant and unless the

focus group is well facilitated or each participant is directly asked to 'participate', quieter, less confident people may not present their story. Secondly, within a group, it is possible that an agenda held by particular participants becomes a specific focus in which other participants may 'feel' the need to agree or disagree because of the forcefulness of other participants. Either way, the 'person', may not be presented.

All participants were initially contacted by telephone enabling me to introduce myself, discuss the study, address any questions they may have to arrange the date for the interview and to organise sending the participant an information sheet for them to read prior to the interview. Interviews took place in a variety of settings chosen by the participant. Most were conducted in the participants' home, others at their place of work (hospital, university, and hotel).

At each interview, I reminded participants of what the study was about and introduced myself, informing them of my professional background. I started each interview with the same question; 'what have been your experiences of cancer services?' and how the participant responded determined the subsequent progression of the interview. This approach provided the space for participants to tell their story as they wanted and still provide me with answers to areas I wanted to explore within the thesis which were around primary and secondary care, communication with cancer healthcare professionals, expectations of cancer care, the emotional impact of cancer, coping with the diagnosis, access to cancer services information, their awareness of voluntary support and what support systems they had. The topics list can be found in appendix seven.

Being both a health professional and a researcher afforded the opportunity of increasing my credibility with the participants and during some interviews, interviewees referred to my professional background at times to reflect I was an 'insider' like them (a health professional) or to indicate I should be aware of a, particular understanding on a topic they were discussing. It also created for me at times the dilemma of sitting between being the researcher and the 'healthcare academic' when certain issues arose during interviews and I expand on this later in this chapter.

In-depth interviews in this study refer to both length of time for each interview and questions asked. Most interviews lasted approximately ninety minutes with Joseph and Mary lasting just over one hour and one interview, Kahn, lasting two and a half hours. The length of time was dictated by the participant regarding how much detail they wanted to provide. Riessman (2005) sees interviews as 'narrative occasions' (p.23) and says researchers need to provide a relaxing environment and have the personal skills to enable the teller to feel relaxed. Cohn and Lyons (2003, p.41) refer to this as creating an atmosphere that fosters "reciprocal and empowering interaction" if they are to produce rich and meaningful data. This was also important in addressing the power relations between the participant and me and I took several approaches in the interview to attempt to produce an environment participants would feel comfortable in, which I allude to below.

Firstly, by asking each participant for their choice of venue for the interview gave choice, familiarity and some control. Secondly, all participants knew the interviews were going to be recorded; for some participants, there was an initial focus on the

audio equipment, being conscious they were being recorded. This, however, lasted only for a brief period as once the participants started to tell their story and felt at ease with the interview, it was clear the recorder was forgotten. By starting the interview introducing myself and anonymising the name of the participant on tape, these actions seem to relax the participants. Thirdly, at times, most of the African-Caribbean participants spoke in patois, when they wanted to make a particular emphasis on an issue they were talking about. I would respond replying back in patois and this seem to create an environment of relaxation for the participant. Fourthly, the relatively unstructured interview format did not seem to pose difficulties with the participants. It allowed them to speak freely and through my engagement asking for clarification on points, or wanting further information on a particular point being made, there was an ease of flow in the dialogue, which I believed enabled the participants to be comfortable with the interview.

Each interview was unique and participants had varied ways in which they approached our interactions; some participants in their interview took a very pragmatic position in how they told their story being very forceful on particular points which were to emphasis its importance in their story (Ngozi, June, Jennifer, Joseph, Lorna, Cheryl). For other participants, the reliving of the cancer journey was painful, not in talking about it but in remembering the poor care received by a loved one; their pain was tangible with silences, pauses, tears and hints of anger at either healthcare processes (Sarah) or healthcare professionals (Kahn, Ebony). Others were hesitant at first (Sharon, Mary, Michael), but as they began to talk through and relive their cancer journey by responding to questions or comments, the dialogue between us became engaging. Considering the sensitivity of the topic, laughter was a common

feature for many when recalling a particular incident. There were, however, as mentioned earlier, times of emotional upset with some participants in recalling events and I was prepared for this. I had tissues handy and asked if the participant wanted to take a break. I did inform participants that we could discontinue the interview, but they all wanted to continue to tell their story.

By way of closing each interview I asked if there was anything more they would like to tell me and invariably this led to opening up another area of their story. Most often their focus was on what could be done better by health professionals in their care of Africans and African-Caribbeans with cancer. However, it was interesting that conversations on their experiences of cancer services in some cases continued after the recorder had been switched off. This tended to occur after I had thanked them for their time and valuable contribution to the research. Where this occurred, generally the participant would say, 'O, I forgot to mention' or 'not sure if this is any good, but…'. Those additions to the story were of interest and I found myself having to record those points in my field notes rather than restart the recorder as those discussions tended to be made when I had already packed away the equipment and I felt I could have potentially lost the impetus and momentum of that part of their story the participant was volunteering, if I attempted to restart audio recording. I contemplated that their actions indicated being comfortable with me and the interview process in wanting to spend more time talking about their cancer experiences. At the end of the interview, I provided all the participants with the contact details of black cancer charities, which they found useful. In particular, those who were carers of loved ones with cancer

I grappled with how to address 'feedback' issues. One point creating increased difficulty with this is the time between being interviewed and the writing up of the findings. During those periods, individuals' attitudes, thinking and actions would have changed and therefore how they would think about the content of the research in the present could make a difference in meaning and recollections of the interviews. The interviews took place between March 2010 and August 2011. Participants who had a cancer diagnosis had been diagnosed between three and eight years prior to taking part in the study. Analysis of the data took place from September 2011 to April 2012 and this time difference between the interviews was relevant as life events move on for participants and recollection of events can alter in the face of such events.

Apart from temporality, interpretive writing is the author's responsibility and interpretations of the researcher as Kuhse and Singer (1998), allude to, may differ from the participant, reflecting the importance of the researcher's ethical approach to the data. My ethical approach to the data is discussed in section 4.2 (p.114). If participants' views on the finding of the study were to differ from mine, the debate about whose interpretations were relevant would have taken us down another ethical quagmire. This conundrum reflects the multiple meanings and interpretations of a narrative and is epitomised by the statement 'every narrative contains multiple truth' (Josselson, 2007, p.534).

Andrews (2008) also provides reflections on addressing divergent interpretations suggesting the author can be explicit in the feedback about these differences, but that does not warrant changes must be made to the analysis. This supports Frank (2002) in his conclusion that the researcher does not have to share the same

perspectives as the narrator. To address these complexities of feedback and potential differences in interpretations, I drew on the steps Josselson (2007) took in her ethical approach to address this issue, which are outlined below. At the beginning of the interview, I explained my interest in the research topic and that each participant's valuable contribution would form the basis of providing an overall picture framed from all the participants. It was explained that any conclusions would be based on collective findings from all participants and would not be a reflection solely on any one participant. They were advised of confidentiality and anonymity but they were also told that they may recognise themselves in the study. I offered all participants a copy of the report and eight made such a request.

The audio tapes were transcribed. Funding was sought for transcribing and two professional transcribers were appointed, based on recommendations from other researchers, including one of my supervisors. The need for two transcribers was due to neither one having enough time to transcribe all the tapes. Reviewing the literature on transcription of audio-taped interviews, I concluded there was no one format to transcribing in qualitative research apart from within linguistics which does have some variables in transcribing conventions (McLellan and colleagues, 2003).
I used verbatim transcription which is consistent with Riessman's (2005) views on transcription. I heeded the cautionary statement by Poland (2002) in relation to verbatim transcription, suggesting that there is care required not only in the transcription but with the quality of the transcription which is produced. This is an important feature raised by Poland (2002) as it refers to the detailed attention of the transcriber to provide a written account of all that has been taped. This requires the transcriber to have the ability to produce clearly typed text, not missing words and providing readable transcription.

Lapadat and Lindsay (1999), like Riessman (2008), purport that interpretation and transcription are not two separate stages but form part of the analytical process. I agree with this; however, it is almost impossible to do when transcription is undertaken by a professional transcriber (which is a service I used), who is not part of the research to physically undertake analytical interpretation alongside transcription.

Tilley and Powick (2002) discussed the importance of the researcher, paying close attention to the choice of a transcriber, particularly in relation to data trustworthiness. I was conscious of potential errors transcribers may make due to the accents of the participants and the interpretation transcribers who are non-researchers may make with the data. I carefully examined each transcript, making corrections on the written text where the transcriber had erroneously made changes to words spoken by the narrator. I agree with Poland (2002) on the importance of listening back to tapes to capture tone of words as well as the spoken word and needing to understand and identify if the tone of words generated a difference in meaning, that is, words spoken might convey one meaning but the tone or pitch of the voice may present another. To address this, I documented my interpretations of these paralinguistic expressions in my field notes.

In addressing Tilley and Powick's (2002) relevant concerns regarding data trustworthiness and Poland's (2002) points relating to quality and rigour of the transcription process, I undertook several actions. Prior to appointing the transcribers, I advised them that the participants may have strong Caribbean or African English accents. This was to forewarn the transcribers as well as to provide

the transcribers with the opportunity to decline the work. Tilley (2003) has indicated some agitation on using transcribers, particularly if they are not part of the research. She argued that the transcribed data can be reflective of the transcribers' interpretation which has the effect of shaping the text presented. I would concur with this view if a researcher were only to use the written text and not refer back to the tapes and collated field notes. However, I did not rely simply on using the transcribed data. Analysis of the data involved interrogating each transcript in detail, listening and re-listening to each audio tape whilst simultaneously reading each participant's transcript of the taped recording and re-visiting field notes taken following each interview.

It became evident listening to the audio tapes that mistakes were made by the transcribers. Words were missing or changed to try and 'correct' what the narrator was saying. One of the participants spoke quite fast with a strong Caribbean English accent and clearly the transcriber struggled. In wanting verbatim transcription I had instructed the transcribers to capture the tone of the interview by placing in brackets when a participant laughed, cried or and where there were pauses.

Listening back to each recording in conjunction with reading each line of the transcription to check for accuracy and re-reading field notes not only reminded me of the context of each interview, but also of further validating the data produced. This was a time consuming but extremely valuable exercise to have undertaken, as it ensured that I was able to interpret what I was listening to and reading, and identify any anomalies between what I heard and what was transcribed. Furthermore, as Riessman (1993) articulates, reviewing the written text and simultaneously listening

to audio recordings aides in (re)capturing aspects of the interview that are not all ultimately transcribed: pauses, silences, rhythm, non-lexical elements and emotions observed during the interviews. I also found it useful to listen to the words used and accents to gain a sense of any emphasis there may have been that again could not be transcribed and that in some cases were specific to the cultural and language backgrounds of the interviewees. Re-listening to each tape brought back vivid memories and images of each participant's interview and aided in not only re-capturing and reliving the interview, but also recollections which fed into the processing and analysis of the data.

In addition to reviewing the text of each interview, I drew on my reflective journal entries which were written soon after each interview, usually on the same day or within 24 hours following the interview. These field notes were an indispensable *aide memoir*. I documented body language, facial expressions, and the environment in which the interview took place, as along with changes in tone of voice and any subtle glances when a certain point may have been made. These paralinguistic features, Hydén (forthcoming) points out should not be ignored as they are part of the narrative experience.

I documented my own reflections on how I felt having heard a story, what were my emotions, my action, reactions to points in the story, how I felt I had conducted the interview, whether I had grasped what I thought were the issues behind the story, what similarities and differences there were between stories and how I had involved myself in narrative co-construction by giving encouraging utterances, clarifying issues and at times affirming points participants made. The use of language, tone of

voice, words, phrases used, was important to capture to give richness to the interpretation of the narrative being presented. Participants revisited points made earlier in the interview, creating a complex interweaving of narratives. These movements back and forth in the narrative were at times spontaneous or came from questions asked; they wanted these questions answered to make a link between what they were going to say and what had been said previously.

4.5 Data analysis: Forming narrative themes

Narratives themes were formulated through loosely using and adapting a thematic framework, developed by Braun and Clarke (2006). The framework has six steps, namely; familiarisation, generating initial codes, searching for a theme, reviewing themes, defining and naming themes. Familiarisation relates to becoming familiar with the data. In the case of this thesis, this involved actions outlined in (pp125-134.). Essentially, the familiarity of the data commenced at the end of each interview with reflections on what took place during the interviews and continued through the process of transcription, reading and re-reading of transcripts, relistening to audio tapes and looking back at field notes.

As part of the analysis, following listening to audiotapes, and field notes, I then recorded on flipchart papers key summative words and phrases from the narratives, which led to the forming of narrative themes. As I was interested in identifying narrative themes instead of coding, I used phrases identified from stories which led to identifying the narrative theme. Some of those narrative words and phrases are illustrated in Table 4.1.

Table 4.1 Examples of narrative descriptions leading to narrative themes

'we don't talk about it [cancer] in our community' (Ngozi) ''I don't think ethnicity is a problem, more class'(Ngozi) ' I felt like I was something on the bottom of her shoe' (Kahn) 'I think there is more openess to talk about cancer in the West Indian community' (Sharon)	Narrative theme ———————→	The narrative on culture, ethnicity & race
'I did examine my breasts regularly but not sure if young Black women know how to do it – who shows them?' (Jennifer) 'More information needs to be better targeted at the Black community' (Cheryl) 'People need to be proactive about their health' (June)	Narrative theme ———————→	The narrative about Screening
''He was calm, gave me time, I didn't feel rushed' (Ngozi) 'You get use to the terms'(Sara) 'He ignored my dad's partner and just spoke to her white friend' (Sharon)	Narrative theme ———————→	The narrative on doctor-patient communication on cancer

'I just gave it over to him [God]' (Sara) 'People just believe everything the pastor says' (Ngozi) 'Its nice to know people are praying for you, it's comforting'(Jennifer) 'Her faith I am sure was what kept her with us a lot longer' (Joseph)	Narrative theme ⟶	The narrative on religion, spirituality and faith
'I wasn't ready. It was just out of the blue after months of 'let's just wait', he wanted to start treatment the next week' (Sara) ' I was on my own when the doctor told me' (Mary) ' So glad I insisted on my GP referring me to the family history clinic, as I didn't feel any limp myself'(June)	Narrative theme ⟶	The narrative of being diagnosed with cancer

Narrative themes differ from thematic themes, as I am not classing small phrases or sentences or other pieces of text together on the basis of theme, I am using pieces of text to show the characteristics of narrative. Thus, narrative themes display the aplot of the story being told, rather than simply presenting a short element of meaning. Therefore, the reader is presented with lengthy extracts to illustrate how a narrative theme was identified. Reviewing the narrative themes was based on what Braun and Clarke (2006) referred to as 'keyness'. This relates to relevance of the theme in answering the research question. In establishing relevance and therefore

'keyness', I based this on the narrator demonstrating a particular issue as important or I judged its importance when other narrators made similar reference to that issue. Taking the example of breast self-examination was a feature discussed in different ways by five of the women in the study, which, alongside other aspects of their story, led to the narrative theme on 'cancer screening'. Working through the Braun and Clarke framework, this process led to converging of narrative themes into:

- Narratives of reliving the cancer diagnosis
- Narratives of healthcare professional-patient communication
- Narratives of culture, ethnicity and race
- Narratives of religion, spirituality and faith
- Narratives about screening

These five narrative themes form the basis of the detailed analysis to be found in Chapter Five and Chapter Six. Murray's (2000) levels of analysis will be used broadly to inform the structuring of the findings. Two of the narrative themes, 'reliving the diagnosis' and 'religion, spirituality and faith', represent Murray's personal level of analysis. The three narrative themes of 'culture, ethnicity and cancer', 'screening', and 'healthcare professional-patient communication' are more representative of Murray's socio-political level. However, as will be apparent in both findings chapters, these themes do not fit fully into these levels, despite their apparent associations with them. The themes are more heterogeneous than this, and each calls up a number of Murray's levels and therefore, in Chapter Seven, the interconnections with Murray's levels and across the narratives themes, will be explored.

4.6 Positioning the author within the narratives

All the participants were aware of my professional background as a healthcare educator with oncology/haematology experience. This provided the context for relationship between the participants and myself. The awareness of 'self' by the

researcher is essential in recognising the possibilities of biases, beliefs which could impact on the interview, the interpretation of the story being told and understanding of the content of the story by the participant (Koch, 1998; Nussbaum, 2001). I was conscious that the personal narratives were not built in isolation but shaped through an interactional, interpersonal relationship between the participant and myself. As a researcher I played the role of questioner as well as listener, wanting to hear, understand and 'feel' their stories.

I had my own beliefs about what were the experiences for black Londoners of cancer services which, were biased against the service not meeting their needs. In dialogue, I attempted to pose questions which led me away from that, wanting to hear what the participants had to say, whether their accounts resonated with mine, but also elements of good practice as well as problematic practice. I was conscious of not wanting to pose leading questions and attempted to ensure each interview started with the same question to give consistency to the study.

I was an insider-researcher cognisant of a number of factors, which interplayed in the interaction with the participants and interpretation of the narratives (re)presented (Bola and colleagues, 1998). Firstly, as stated earlier, I am a health professional with experience of oncology and my knowledge of cancer and the healthcare system gave me an advantage in understanding medical jargon participants used and an appreciation of some of the challenges faced by healthcare practitioners from the narratives (re)presented. However, I did at times find myself questioning approaches taken by a number of clinicians and nurses towards some participants. I did not voice those questions to participants, but they did shape some of the questions I asked, such as asking 'how' or 'why' questions to follow up on a particular topic.

Secondly, I shared the cultural background of the Caribbean (and particularly closely the Jamaican) participants and therefore had a tacit understanding of certain phrases, gestures (for instance, sucking of the teeth, colloquial words used), which added to the interactions within and interpretations of the narrative. I could resonate with some of the issues raised by women within the study such as Sharon when she spoke about being the nurse in the family and frequently called upon by family members to explain and give advice on symptoms or whether to follow the advice given in doctors' consultations. I understood and appreciated the health gatekeeper gender role within the family and the challenges of trying to support the men within the family on self-assessment and making use of primary care services for screening. Thirdly, however, my position as a healthy person interviewing some participants who had a life-threatening diagnosis places me in a position of 'outside looking in' on their experiences, Murray (2000).

Pitts and Millar-Day (2007), forewarns researchers to consider ways in which to lessen the distance between themselves and the participant. I recognised my position of potential power and during the interviews, I considered it within the context of how the stories unfolded and the direction the stories were taking. I wanted to mitigate that position by framing questions in a way that helped to make the participant comfortable, aiming to take the focus away from my professional capacity and informing each participant what they wanted to discuss was their prerogative. Hence, the loose format of the interview and questioning process served a dual purpose; to open the interview and to place the participant as centrally the important part of the relationship between the participant and myself.

During some interviews narrators questioned me about the study: why I am doing the study? What did I want to achieve? And they wanted to know if the outcome of the research would help others. Being questioned like this, I believed was an indication not only of the participants' interest but also in some way changed the power balance between us. They took some power in the situation as agents of advocacy and change. I found myself at times asking lengthy questions, which is an indication of my inexperience and clumsy questioning, which meant on occasions participants required clarification of what I was asking.

On occasions, I was placed in a dilemma of finding myself in the position of researcher but also as a health professional feeling the need to seriously consider whether I should be advising the participant. In particular with Ngozi, who expressed anxiety about not knowing the results from a second scan. I had a conflict in whether I was stepping out of the role of the researcher and becoming a professional by giving advice on what actions Ngozi should take. I felt professionally and ethically responsible for advising her to follow up on the scan results. She contacted me four weeks after the interview to inform me of the results, which were negative and expressed her appreciation for encouraging her.

Some narratives were emotional, in particular Sara's story about her father, with whom she was extremely close. Her feelings of whether she had done enough to support him, the regrets of not pushing him to go for screening earlier, brought back memories of my own situation with my father who had died. Initially Sara was hesitant in taking part in the study as she thought it might have been too painful for her, but at the end of the process she found it highly cathartic and benefited from taking part in the research as she was able for the first time to talk about her father's

experience from her perspective. Seven other participants also specifically talked about the 'therapeutic' value of taking part in the research; they were being listened to without having to consider the feelings of others (family or friends). It gave them an opportunity to tell their story and a sense that they had a story to tell which was valuable to hear and learn from. This was an unexpected positive outcome for me and is discussed further in Chapter Seven.

My assumption about the ethnicity of Kahn's wife was to believe it was the same as Kahn and when he responded to taking part in the interview, the information on the flyer clearly stated 'African and African-Caribbean Londoners' experiences of cancer services', I assumed his wife was either African or African-Caribbean. It was not until towards the end of the interview that Kahn mentioned his wife was Irish and white. This was a valuable lesson on researcher assumptions. Kahn's narrative was included because there were issues surrounding racism and prejudice, and with the increasing number of mixed race relationships in the UK, it will mean that such situations will occur with the possibility of different and similar issues being uncovered in future illness narrative research.

4.7 Conclusion

The research questions provided the foundation for focussing the research and shaping the list of topics for interviewing. There were challenges of gaining ethical approval in narrative research but in retrospect the LREC interview provided a useful experience to discuss the research and give beneficial advice on additional areas of importance to the research. Processes were put in place to foster an environment which encouraged a dialogue. Conducting interviews with a limited structure appeared to be an enabling feature in allowing participants to freely tell their story

with minimal interruptions from myself. Creating a relaxing environment by not only having the interview take place at a venue of their own choosing, but by me also being comfortable to talk in patois if they choose to do so, was an important factor in harnessing detailed knowledge about their experiences of cancer services. From the depth of detail provided by participants and in jovial but also at times emotional points during some interviews, I felt the participants trusted me since they seemed to feel free to tell their story. I was aware of my own emotions and found at times I was getting into the 'emotional space' of the participant, concurring with or positively acknowledging statements made by the participant. In the analysis and discussion chapters, I address these issues further.

Conducting the in-depth interviews was a humbling experience in how participants were willing to share their stories to a stranger. The process of reviewing transcribed data generated insights and lessons into the importance of not solely relying on written text but the need to revisit audio tapes for accuracy and to recapture paralinguistic moments within the interview which are impossible to do in written form and yet they can add further richness to the narrative. It was especially evident I was co-constructing the story with the interviewees with utterances I made which at times were supportive of a particular statement a participant may have made, agreeing with issues expressed or pausing the interview at a particularly sensitive time.

The multiciplicity of meanings from personal narratives is indicative of the interpretation nature of narrative research and the challenge faced when considering ethics. However, steps were taken to address this whilst respecting the privilege on being allowed 'into' a part of someone's life. Utilising the main tenets of Braun and

Clarke's (2006) framework provided a constructive basis for identifying narrative themes.

SECTION THREE: FINDINGS

CHAPTER 5: FINDINGS, PART I: THE NARRATIVES ON CANCER DIAGNOSIS AND NARRATIVES ON RELIGION, SPIRTUALITY AND FAITH

5.0 Introduction

This chapter aims to introduce the narrators and present an analysis of two of the narratives, namely; 'reliving, the cancer diagnosis' and 'religion, spirituality and race'. I conducted twelve interviews and the interviewees were nine women and three men. The narrators were African and African-Caribbean originating from Ghana, Nigeria, Kenya, Jamaica and Trinidad. Seven women and one male participant had previously been diagnosed with cancer, which included; breast carcinoma, carcinoma of the colon, prostate cancer, lymphoma and carcinoma of the kidneys (see table 5.1).The male participant diagnosed with cancer was included in the study because he not only shared many similar experiences to the female participants, but also presented a different gender perspective on some emerging narrative themes, which will be presented later in this chapter.

Two male participants were widowers, one whose wife died in 2004 and the other whose wife passed away in 2009. Both women had breast cancer. Another participant was a daughter whose father died in 2010. Inclusion of the stories of the widowers and the daughters, was valuable in presenting another perspective on illness narratives, which related not only to the impact of the illness on the person diagnosed with cancer, but also the impact of the illness on significant others. Lastly, one narrator's story related to breast and cervical screening rather than a cancer

diagnosis. Although her results were negative for cancer, her story shared significant parallels with participants who had cancer.

Each participant's journey was unique, but commonalties were observed within their stories which might be expected to yield some degree of generality between the narratives, leading to the possibility of identifying narrative themes. In re-telling their stories, participants invariably had narrative flashbacks which led to 'jumping' back and forth between topics, as talking about one issue triggered memories of other experiences, which the narrator thought important to include within their story. Even across these fragmentations, narrative themes, which straddled all the participants' stories, emerged. However, as will be observed both in this chapter and Chapter Six, the impact of cancer experiences were not the same for all.

A snapshot of each participant is presented in Table 5.1, the aim being twofold: to provide the reader with a 'picture' of each narrator, with the intention of assisting in recognising participants, and to enable readers to relate the analysis to their individual characteristics. Participants' names have been changed to maintain confidentiality. All the interviews took place between March 2010 and August 2011.

Name	Age ***	London area participant resides	Age at time of diagnosis	Diagnosis/relative's diagnosis	Profession	Health status at time of interview	Ethnic origin	Marital status at time of diagnosis	No. of children	Place of birth	Treatment
Ngozi	38	East	33	Carcinoma of the kidneys	Student	Well, disease free	African	Single	1**	Nigeria	Surgery
Mary	60	North	50	Carcinoma of the breast	Health care assistant	Well, disease free	African	Married	3	Ghana	Mastectomy, chemotherapy and radiotherapy
Jennifer	57	West	55	Carcinoma of the breast	Retired midwifery senior lecturer	Well disease free	Caribbean	Married	1	Jamaica	Mastectomy and reconstructive surgery
June	52	West	50	Carcinoma of the breast	Health visitor	Well disease free	Caribbean	Single	None	Trinidad	Mastectomy
Sharon	34	South	32	T-Cell Lymphoma	IT Specialist	Well disease free	Caribbean	Married	1**	Trinidad	Bone marrow transplant
Lorna	53	North	45	Carcinoma of the breast	Home carer	Well disease free	Caribbean	Single	1	Jamaica	Mastectomy and reconstructive
Ebony	59	East	34	Carcinoma of the breast	Former company administrator	Well disease free	Mixed race (Nigerian and white British)	Living with partner	None	England	Mastectomy
Sara	51	North	Father was 60	Carcinoma of the colon	Father retired railway worker. Sara specialist nurse	Father died aged 70	Caribbean	Living with partner	Father had 4 children	Jamaica	Surgery
Kahn-widower	56	South	Wife was 50	Carcinoma of the breast	Wife was a housewife, Kahn formerly a council worker	Wide died aged 53	Kahn Kenyan wife Irish	Married	1**	Ireland (wife) Kahn - Kenyan	Mastectomy and chemotherapy

Joseph-widower	79	West	Wife was 60	Carcinoma of the breast	Wife was a housewife Joseph retired bus driver	Wife died aged 65	Caribbean	Married	10 *	Jamaica	Mastectomy
Michael	57	North	53	Carcinoma of the prostate	Formerly mechanic	Well disease free	Caribbean	Married	8	Jamaica	Prostatectomy and hormonal treatment
Cheryl	53	East	NA	Screened for breast and cervical cancer – negative results	Health visitor-lecturer	Well	Caribbean	Living with partner	None	Jamaica	NA

Table 5.1 Synopsis of participants

Key -NA= not applicable

* formed from re-marriage- combined total of offspring created from both Joseph and his wife having children from their previous marriages

** Three participants had children under 15 years of age at the time of diagnosis

*** Age at time of interview

As described in the previous chapter, five main narratives themes were identified from the autobiographical accounts. This chapter analyses the narrative themes: 'reliving the cancer diagnosis', 'religion, spirituality and faith', 'screening', whilst Chapter Six addresses the narrative themes, 'healthcare professional-patient communication', 'screening' and 'culture, ethnicity and race'. There were overlaps between some narrative themes, demonstrating interconnections and interplay between and within narrators' sequencing of their stories. This also reminded me that recalling past events can be 'messy', but what is present is a plot to each unique narrative. At the same time I was conscious of how my perceptions, feelings, position and style of engagement, could affect emplotment. Such positioning and reflexivity were discussed in detail in Chapter Three (section 3.5, p.108) and Chapter Four (section 4.8 p.137).

I presented the analysis in a way that is consistent with my dialogical approach to the research process. Such an approach I considered valuable and appropriate as it provided a platform for participants' feelings and experiences to be expressed through language. This granted me insights into their experiences of cancer and how the diagnosis affected their life and shaped their view of the social world. The analysis is therefore presented complete with questions or comments from me to whom the narrator responds and thus it shows the building dialogue we engaged in.

All participants spoke English but during the interviews almost all the Caribbean narrators reverted to patois/Caribbean English. Where this has occurred I have translated the words into UK English, but have left in place what might appear as grammatical, lexical inaccuracies, as they are representations of the originality and uniqueness of the narratives provided and of the dialogism between myself and these participants. Caribbean English not only represented a particular meaning within the story, there was also an implicit understanding by the participants that I would know what a particular utterance, tone of voice or element of body language represented. Being able to speak in such a free manner gave these interviews a sense of 'naturalness' in the dialogue between the participant and myself. The 'naturalness' I refer to is the everyday discourse between individuals who share a tacit understanding and awareness of cues and interchanges which do not warrant explanation within a common, though not identical, language and cultural community. This interchange of accents and words used, I believe, was an indication of a number of issues. Firstly, it signified the comfort the participants felt with the scenario of being interviewed; secondly, it presented their story in a manner which possibly provided a better sense of how they experienced cancer services since I was able to understand what particular words, phrases and paralinguistic elements meant within the context of the story being told.

Lengthy extracts from particular participant exemplars will be used to represent how each narrative theme unfolds. In addition, smaller narrative accounts from other participants will also be presented to reflect either an additional or different perspective on the narrative theme. (P) is used to

denote long pauses in interviews where there was an unusual length of silence for that participant. Such silences generally lasted approximately five seconds. To aid in clarification and interpretation of words or phrases used by participants whose narratives were presented in a mix of Caribbean English Patois and UK English, I have translated those words into UK English and placed translated words into brackets [ ].

In some interviews there were many occasions where interviewees had limited prompting from me, and my utterances of 'right', 'okay' gave narrators the freedom to talk with minimal interruptions. In these cases, the absence of shown contributions from me accurately reflects my lack of speech within the narratives. Finally, where it appears significant from my field notes, I also made reference to body language elements, which importantly affected any narrative turn within the interview. Having provided an overview of the narrative themes in Chapter Four and introduced the narrators earlier in this chapter, analysis of their stories is now presented.

5.1 The narrative of cancer – reliving the cancer diagnosis

Being informed you have cancer stirs many emotions including, fear, anxiety, anger, a heightened sense of one's mortality and how one's life now seems to be potentially shortened (Karbani and colleagues 2011; Scanlon, 2004; Thomas and colleagues, 2005). How the diagnosis is presented and the way an individual responds to the diagnosis is full of complexities which are underpinned by gender, culture, ethnicity, types of relationships people have with family and friends, previous experience with health professionals, as well as language used by health professionals, which at times may be considered

conflicting and confusing (Abdullahi and colleagues, 2009; Box, 1998; Curtis and Lawson, 2000; Henderson and colleagues, 2003).

'Life consumed by appointments' (Sharon) is a statement many narrators echoed which underlined the disruptions in family and working life, the increased stress and the increased sense of vulnerability the diagnosis created. Reliving that period of time in their life highlighted complex relational factors of the self, societal and cultural factors, but also depicted the tenacity and strength of participants in facing the challenges of a cancer diagnosis. The commonalties of experiences in reliving the cancer diagnosis generated sub-narratives which I termed; 'Do I have a story?', 'Unprepared for the diagnosis' and 'Life's bad breaks'. Although three exemplars will be treated here as representative of the eleven participants who had a cancer experience (either through being a patient or a carer), extracts from some of those narrators will be used to illustrate either a similar or different perspective on the same sub-narrative theme. How each narrator tells their story of reliving their cancer diagnosis and how the illness has impacted on shaping their response to life following the diagnosis, reflects Hydén's (1997) concept of illness as narrative and Bury's (2001) concept of moral and contingent narratives.

5.1.0 Do I have a story to tell?

'I am not special' (Lorna) was a common comment participants gave when I met them for interviewing. However, as the interviews progressed, participants began to realise they had something of value to share. All

participants were willing to tell their story. For some, there was a story of accomplishment, of overcoming adversity; however, survivorship did not diminish some participants' accounts of their difficult emotions about lost opportunities of parenthood, fertility and feelings of not being respected by healthcare professionals. For others, particularly the widowers (Kahn and Joseph) and the daughter (Sara), recollections were painful; the pain related to memories of poor care, being made to feel unimportant by health professionals, delays in diagnosis and regrets.

June's story represents well other participants' journeys when being given their diagnosis. Her narrative also falls into Hydén's (1997) category of illness as narrative both in the way it talks about the illness and in how it portrays living with cancer. At the start of June's interview, she made a comment characteristic of some of the other participants:

> **June**: I don't think I have a story.

However, as her story unfolds, like other participants, there was a story to be told and one which I found humbling to hear. Believing that her story was unimportant was reflective of her philosophical attitude to her cancer diagnosis and to life, which was to not to let obstacles get in her way. She did not think she was special and had a 'no fuss' attitude to situations. This view of not being special and not having anything of significance to say was also evident in Jennifer's, Sharon's and Lorna's narratives.

June: I just went to the cancer services because of something I read and because of my family history, paternally, of breast cancer basically. I had insisted that my GP referred me to the family history clinic since I have a family history of breast cancer. I'd been seen at the family history clinic for like almost seven years, and in 2008 I had my yearly check and a lump was discovered. I didn't feel anything so I was really thankful. Had a positive biopsy, then had, umm, lumpectomy, the lump was removed then, umm, discovered that really I should have had my mammogram done even before the first biopsy but, for some reason, was done just the day before surgery. They found that there were wider margins, so had to go back in basically, was tested again with another biopsy, which again came back positive.

MB: So two lots of positive biopsies within a short space of time?

June: Yes. The first surgery was January and then I think the next biopsy would have been like the cause the surgery was in March, would have been like in the February.

MB: Right.

June: When I saw them at the follow-up clinic, I was told that they were puzzled, and their exact words were 'I'm presenting a conundrum to them' because they wasn't quite sure what was happening because it seem as if nothing seem to be there.

MB: What did the oncologist mean by that?

June: When they tested the biopsy tissue, which they had taken in surgery when I had the mastectomy, there were no cancer cells in it.

MB: They didn't find anything?

June: Nothing, yeah, that's what I'm saying.

MB: So how did they explain this?

June: Well, when I saw the oncologist on what the report actually said in the summary letter was either there were probably wasn't anything there anyway, or either that it was so tiny, that it came off with the needle biopsy. So it's not necessarily saying that it wasn't there at all, which is always a possibility.

MB: So it's almost saying that the rest of the tissue, breast tissue, hadn't been affected.

June: Which is what was showing at the last pathology. I think for them as I say, they were puzzled, so it's like okay.

June was extraordinarily accepting about the potential loss of a breast, which

may have been unnecessary. She had gone through two surgical procedures in a very short space of time and the post-surgery results would seem to suggest a mastectomy may not have been necessary. Yet she did not speak with any anger, malice or resentment when she made the comment.

> **June**: So it's not necessarily saying that it wasn't there at all, which is always a possibility

.I interpreted this turn in the narrative as wanting to believe cancer may have existed to legitimate the need for the mastectomy, as to think otherwise may have been too painful. June's reflective statement, "so it's okay", was said with her laughing at the situation of being seen as 'special' by clinicians. The laughter seemed to represent not only her perceptions of being 'different' but also her position as a basis for learning which she later alluded to in her story. Later in June's story she referred to a time in her cancer journey where the service let her down during the diagnostic process.

> **June**: So she apologised but it wasn't really like the registrar's fault okay, it's part of her role, but it wasn't the absolute whole, you know, their responsibility, because to me really they should have done the mammogram first, basically, that's what I would have done if I was a radiologist, I would have done, one, two, three.
>
> **MB**: What do you mean by that?
>
> **June**: I had the examination. Let me confirm this first [referring to the radiologist]. Well let me have that mammogram at least, and the thing that made it for me Marvelle was when she kept saying, the radiologist that is, and I'm only saying this direct because you are a professional too, should I do the mammogram? Should I do this right now? And I'm thinking she's asking me as if I am a colleague and I'm saying well of course do the mammogram but then she said, oh you are due one a couple of weeks later. But Marvelle, I'm thinking we can do it now, do it today, why not do it today, you've already seen something suspicious. I didn't forget it Marvelle. And that is what got me Marvelle, that bit of it, I saw a clinician, [radiologist] being part of the whole team, it's not just a surgeon's role, it's their bit as well.

June's narrative implies there was resentment at the radiologist's indecisiveness and she raised her voice at this part of the interview, not in anger but in apparent disbelief at the actions of the radiologist. The memory was still very vivid and raw. June believed the radiologist wanted some form of agreement for actions she (the radiologist) was taking. June drew me into her story, referring to me not only by name but also by my profession, which I believe was a way to give legitimacy to her story as she expected that I would, through my professional background, understand how the system had failed her. At this point in the narrative account two professionals (June is a health visitor, me a health academic) were engaging in conversation, with me being seen by June as having 'insider' knowledge and understanding of the organisational processes of the NHS. Later in her story, June linked the problems she had in the clinic and the failings of the radiologist as being an 'inevitable consequence' of events which in her mind were always going to end in a cancer diagnosis.

June: I was waiting in the clinic for ages and when I was seen it was not by my usual doctor and the one I saw was the doctor who didn't make sure the mammogram was done. So from the beginning, there was a trend of things not going right.

She appeared to make relational links between events. Problems in the out-patient clinic (different doctor), indecisive radiographer (mammography not undertaken) and the 'inevitably' of being given the diagnosis of cancer is an illustration of Bury's concept of contingent narrative in how it relates to situational events which are then wrapped into the development in a belief of a cancer diagnosis being an outcome. These events could be considered

problems with processes and procedures, but from her narrative account these incidents were a catalogue of things going wrong and were 'signs' of an impending negative outcome (being diagnosed with breast cancer).

There were some areas of ambiguities in her story when she stated; "so it's not necessarily saying that it wasn't there at all, which is always a possibility" and sense of 'fate' at play 'so from the beginning, there was a trend of things not going 'right', the narrative presents how issues can become interrelated and thus interwoven with the narrative as Hydén (1997) articulated. Seemingly random events interlinked to form a story. Lorna, like June, also presented in her narrative relational links to explain why she 'developed' cancer.

> **Lorna:** My aunt had breast cancer, my younger sister had breast cancer when she was 32 years old and so I knew I was going to get it too.

Considering Lorna was one of four sisters and neither of her parents had developed breast cancer, it was not inevitable that she herself would; but intuitively, like June, she believed she was always going to develop the disease. Both June and Lorna were reflecting Hydén's idea of how individuals with a chronic illness attempt to provide an explanation and a cause for the illness. In Lorna's narrative, she suggested the basis for her cancer was genetic and therefore developing cancer was, as Lorna articulates, "not a surprise". Later, however, Lorna's narrative presented an extremely positive outlook when comparing herself to her aunt, who had died, but her sister who was diagnosed in 1984 had survived and therefore she viewed her sister's survival as a positive sign for her own survival. Both the narratives depicted

some of the complexities of explanatory narratives and provide counter-narratives to dominant story lines (Andrews, 2002); when, for example, Lorna, like June, who also had a family history of cancer, gave a narrative that did not present a story of negativity and despair of having developed cancer. Instead she viewed her future in a positive light.

I returned June to an earlier point she made regarding the dialogue she had with the oncologist, as there was a suggestion of a shift in power relationships between her and the clinician that I wanted to follow up, particularly given her own medical status, and her place as a BME patient within white-dominated medical practices. In the ensuing dialogue, however, another factor, gender, emerged as important.

> **MB**: It's interesting you said earlier the oncologist was upset by the decision that had to be taken.
>
> **June**: No, when I say upset, I think she was upset by how it worked out, with my mammogram not being done, I think embarrassment really.
>
> **MB**: Okay.
>
> **June**: I could see the pain on her face and I think at one time she just left the room because it was like I think painful for her. I could feel it you know, like it was almost like she was going through what I was going through. I could see it on her face, so she had that empathy, that's what she was putting herself in my position. And her face really showed it, and at one point, I thought I was going to see tears really. You know, I could feel it, yeah.
>
> **MB**: And I suppose when you have reactions like that, it almost makes you feel that maybe things didn't go well, but at least they (the professionals) understand how a patient feels.
>
> **June**: Exactly. Cause a lot of people saying oh I should do dis [this], I should do dat [that], I should complain, I should have the law involved, and I'm thinking, I don't want to do that. Not that there probably wasn't a need for a certain something, but I just felt I don't particularly want to go down that route. I really thought the doctor was genuine, you know.

We got it wrong and apologising for that. She was open and honest with me.

Explicit in June's story was the importance of truthfulness. Her narrative suggested that the clinician explaining what may have been mistakes in the care she received was enough for her not to want to follow any legal process. June's narrative suggested there was a moment during the consultation, which represented a shift in the relationship between them, from being a clinician and patient to two women sharing a moment. June's narrative portrayed the emotions of the oncologist, and she perceived the oncologist as empathising with the potential devastating consequences of having major surgery which impacted on femininity. Within this aspect of her narrative, there seemed to be a reciprocal intersectionality between the two women, in which gender and illness rather than ethnicity and illness were significant to June.

June's narrative went on to articulate her views regarding her illness and the way she approaches life and living since the diagnosis and surgery, illustrating Bury's ideal of moral narrative; that is, giving an evaluative dimension by linking the personal with the social, but at the same time almost explicitly putting Bury's (1991) notion of illness as biographical disruption into question.

> **June**: I made a conscious choice well to not to let it affect me negatively, because I could become very depressed and angry and what's the point, I'm not that way anyway, so I not going to let that bring me down. I still have my life to live, you know. What's the point fighting? To me fighting battles that you don't really need to fight really,

and it's not I don't see it as a battle to be fought, just an experience. For me, my take on it is hopefully something would have been learned from this, you know, something positive would have come out of it and learn to benefit other people. To turn it positively. Moving on and making positives out of something that's not always so positive, because I think you can have positivity out of things really.

Here, June stressed the importance of lessons being learnt by the clinicians from her experience. Her narrative suggested she provided them with a challenge that could have benefits for other women in the future. This altruistic narrative is not uncommon amongst cancer patients, and other participants, Lorna and Sharon, also expressed such sentiments. More generally, learning from experiences was a common element in seven participants' narratives, but the learning was not always aimed at the same audience. June, Sharon, Sara, Jennifer and Lorna, focussed their concerns about learning on improving services, a goal for healthcare professionals. Ebony and Kahn wanted black people who needed to use cancer services, to know what difficulties there can be with health professionals and what they can do to support themselves.

June's narrative presented a view of how she believes energy is best spent on living and not having cancer dictate her life. She wanted clinicians to learn from their mistakes, a feature shared by other participants (Mary, Lorna, Sara). However, one participant's narrative (Kahn) reflected a different response to poor care. Kahn's account suggested that unacceptable attitudes towards him and his wife led him to instigate a formal complaints process. In his narrative, the lack of respect and the dismissive attitude shown by one oncologist caring for his wife had a devastating effect on both him and his

wife. His narrative is presented more fully in Chapter Six, section 6.1.2 (p.200).

June's narrative suggested she was not going to allow cancer to impede her life or affect what she does or how she feels. Even though she had other illnesses unrelated to cancer, her narrative account presented her as being forthright, cheerful and having a positive outlook on life. Her story reflected actions taken to not allow cancer to impact on her activities and she aimed to live life on her terms and not have her cancer experience affect her lifestyle and behaviour negatively. Her narrative suggests she saw cancer as something to deal with and live with but not to be dictated by it. This positive approach is demonstrated by other participants, Lorna, Ebony, Ngozi, Mary and Michael and supports what Bury (2001) refers to as normalisation (see section3.1, p. 97). June's story appeared to suggest her positivity accounted for how she coped with cancer, enabling maintenance of a sense of self-value with yet another illness. This could suggest that cancer may not have been biographical disruptive in Bury's (1991) terms, but an ongoing life event that she, like several other participants, dealt with.

5.1.1 Unprepared for the diagnosis

This sub-narrative was evident in the stories of five participants when reliving their cancer diagnosis. The narratives of some participants (Sharon, Ebony and Mary) articulated having their sense of hope shattered, or that a time clock had started on their life, but for all participants there was an uncertain future, which came with being told they had cancer.

Sharon's narrative reflects the accounts of four other participants (Mary, Ebony, Kahn, Sharon) relating to support, feeling out of control and cancer being instrumental in building unlikely social relationships. Here, Sharon's account again reflects Bury's idea of contingent narrative, placing the start of her cancer journey at the event of giving birth and contextualises what Hydén refers to as how the narrative links events into providing a whole which creates the illness narrative.

> **Sharon**: When I was in labour having my beautiful daughter in 2008 they found that my blood platelets were low and that is when this whole thing about cancer started, although actually at the time I didn't know that was what it was, but that was the first presenting signs that something was up.
>
> **MB**: What actually happened after that?
>
> **Sharon**: They referred me to a professor and he is supposed to be top notch in terms of lymphoma and haematology and he himself he was very, er, cautious about giving me a diagnosis and the fact that I had just given a birth he thought it might have been some sort of infection you know. He was baffled because I looked so well and felt well. He had never seen a case like me being so well with this T-Cell Lymphoma.
>
> **MB**: So was that the time the cancer diagnosis was made?
>
> **Sharon**: Well sort of. They still weren't sure. I was back and forth for many months to the hospital having follow ups and investigations, you know blood tests and so on as they were still unsure what I had or what to do. I was trying to get on with my life but it wasn't easy living with the uncertainty and keeping a sense of hope. You know with the constant investigations, blood counts, harvesting, scans, bone marrow biopsy, after a while you kind of come to terms with the terms. So on my last visit to the clinic I hadn't expected him to say 'time to treat' and certainly not to say start next week. I was totally blown out of the water. It took me by surprise. This cancer thing was really not on my agenda at all because all the time he kept saying 'let's hold on' so when he eventually decided to treat and he said we will start next week. The story is coming out now (p).

This was a significant turn in Sharon's narrative. She went silent for some time after making the comment, *"the story is coming out now"*. This was said when we were about forty minutes into the interview. She remembered how she felt at the time of being told treatment would commence, treatment, which she acknowledged in her narrative account was the confirmation of a diagnosis she had hoped would not be cancer. This moment was profoundly felt by me and Sharon through those seconds of silence (5-7 seconds). Sharon's account suggested how she reflects on the moment that was to have a significant impact on her life. From that point on in the interview she became more confident, more self-assured, manifested by her becoming more animated with her gestures to emphasise meaning, as well as comments she made in telling the rest of her story, such as, "I'm really glad I agreed to take part [in the study] now as I probably would not have talked about things in this way." This change in interaction was of interest as earlier in the interview Sharon was quietly spoken and unsure of whether what she had to say was important.

Becoming familiar with medical terminology, as Sharon says, "you get used to the terms", is not uncommon in patients with a chronic illness. Like other participants, Sharon's narrative illustrated understanding of medical jargon and medical terminology which is interwoven throughout her narrative. Sharon spoke with ease of 'platelets', 'harvesting', and 'petchiae'. Kahn, in his narrative account, was very detailed in explaining experimental drugs and the different stages of drug trials. Such familiarity with medicine, as depicted by Sharon and Kahn, is not usual in everyday dialogue, but here forms an

important part of illness narratives within which people are inextricably tied to healthcare services. Sharon's narrative went on to give her account of the unsettling nature of being diagnosed with cancer.

> **MB**: So the suddenness of the decision to treat was unexpected?
>
> **Sharon**: Yes, I was not prepared really. The next week came and I hadn't heard from him [the doctor] and I got a call from the hospital asking me where are you, you were expected and I said first of all you didn't tell me where to come and secondly I have loads of questions, how long will I be in hospital, what will it entail, I had my baby to plan arrangements for. How will it affect me? You know, erm, I had two sides of A4 pages of questions that my Macmillan friend helped me to put together because tings [things] I hadn't even known about like infertility and all those tings [things] you know and that was one area that I found wasn't handled well by the hospital, but I'm not really laying blame anyway, you know.
>
> **MB**: How was the treatment?
>
> **Sharon**: He said about three weeks, but it turned out to be four months of treatment and it was a lot really to take in. Looking back now it wasn't as bad but you know when you are going into a situation you always perceive it to be worse than it is. I think the issue of infertility really hit me hard even though I had just had a child you know, people will say I am fortunate and I know I should be, she is really precious and she is my life saver, if I hadn't had her, who knows what might have happened. Maybe the cancer would have been more difficult to control. But the fact that they had taken so long to come to a diagnosis. I felt they could have had some foresight. If this is the road we are going down then we could have started talking about my options but I think it is all about funding. I already have one child I would not be seen as a priority, (p). I don't know, I just feel so robbed. (p) I didn't know fertility would be a problem until my friend asked me if I was going to do any harvesting of eggs.

Sharon's narrative reflected on the time of diagnosis and treatment, seemingly to refer to her experiences as possibly not having been too difficult. However, considering her initial hospital stay was to be for three weeks, but lasted four months, this would suggest that the period of time of her treatment was not without its challenges. Her story depicted the impact of temporality on perception of experiences and how reflections can be affected by time. Her

narrative suggests she had an understanding of the wider socio-political context of the availability of fertility treatment and what her chances were of being able to access it under the NHS. Sharon's narrative indicates awareness that funding for fertility treatment was finite and her opportunity of accessing that treatment under the NHS would be almost unattainable. Her story thus again illustrates Bury's (2001) idea of moral narratives and presented an evaluative dimension in outlining the impact the illness potentially has on altered relations between the body (infertility), the self (femininity) and society (health policy).

The lack of time to digest the situation, to plan, to make arrangements for her daughter and how her husband would cope having just started a new job, left Sharon feeling overwhelmed and no longer in control. The feeling of not being in control of events was implied also in Michael's and Mary's narratives. Their accounts shared with Sharon's how reliance on others added to participants' sense of vulnerability when diagnosed with cancer. They were grateful for the help but wanted things to go back to 'normal'.

> **Sharon**: Even though my mother-in-law was there to help I just wanted us to be back to the three of us.
> .
> **Mary**: I felt scared when I was alone at home on my own. One day I called my husband at work, I couldn't stay in the house. He came home took me with him to work and I stayed there until he finished. I felt so silly to be scared and being a burden to him.

Feeling out of control in Sharon's narrative would suggest the illness was impacting on her identity as a mother and wife. The anxiety attack which led to feeling out-of-control created by the illness for Mary, underpinned the deep

psychological trauma cancer can have on self-confidence and this concept of being out-of-control is not extensively explored in the typologies of Bury (2001) and Hydén (1997) but in these narratives it is a significant feature in their cancer journey.

A third element of these 'unpreparedness' narratives relates to unexpected new social networks. Sharon's story makes reference to how the organisation of the cancer service provided a platform for unexpected new friendships to be formed.

> **Sharon**: The hospital had what was called ambulatory care, which was a hotel-like building, which patients went back to after their treatment. It was great. Coming out of treatment and going there instead of a long journey home was so good. I think it was the best way to be treated really because as when all of us as patients had finished treatment for the day, there was this colony of people with bald heads and there was such camaraderie and you know, I made two good friends through that. One is actually a gay man and the other is a white woman and in everyday life I would probably never have met them or even built any relationship with them. I mean cancer is a real equaliser and even though I have a great family and friends, they [the cancer patients] know more than anyone else in your life would understand what I am going through in terms of actually having cancer.

Sharon's narrative strongly pointed out that although she has a loving family and a good network of friends through the church, that only another cancer patient will ever truly understand what she is going thorough. The unexpected friendships she referred to in her narratives which developed during her time of hospitalisation, appeared to transcend across race, age, gender and ethnicity. These identifications were backgrounded at this point in the story; cancer patient identifications were paramount. Sharon's account implied such relationships with other patients were a powerful support structure for her. This part of her narrative is reflective of Bury's idea of strategic management,

in which support is harnessed from other cancer patients in whom talking about her experiences of treatment, its impact, how she feels about cancer, her own anxieties, there is an unspoken understanding that can only be understood and shared with by another cancer patient.

Significantly, all the patients around Sharon had, like her, a haematological cancer, which would again suggest an implied understanding of the impact on treatment, which may not be the same for other patients with a different type of cancer, potentially experiencing different symptoms and side effects related to their cancer. In addition, the narrative also depicted how individual experience becomes what Hydén (1997) refers to as a collective experience, which only another cancer sufferer can understand. Sharon's narrative encapsulated being part of and gaining comfort and support from being a member of the 'cancer community'. It suggests that this community played an important part in helping her to cope with the treatment.

Sharon's narrative account of having access to such support created by how her care was organised, was not apparently typical for other narrators. The narratives of Michael, Lorna, June and Ebony, indicated they found solace with friends and the church as opposed to healthcare professionals providing information and advice on voluntary groups. Ebony's narrative expressed how she discovered a charity for black women with breast cancer, which was the start of her regaining self-confidence. The disruption cancer caused for Ebony was compounded by not having close family ties and caring for a chronically sick partner. Hence, uncertainty about managing herself, her

partner and navigating around treatment, hospital admissions were particular

implications illustrating the chaos cancer can create, and the recognition of

significance such narratives present depicting the need for support.

I wanted to further develop with Sharon what she meant when she mentioned

in her story about cancer being an 'equaliser', something she related to

everyone in relation to the possibility of unexpected loss.

> **MB**: So cancer is an equaliser?
>
> **Sharon:** Yes. I have seen old, young, black, white, Asian, gay, straight people go through this cancer thing and you realise this is how the other half live you know. People walking out there and they don't know about me what I am going through but those guys at the hotel did. If people watch me with my scarf as that is how I chose to wear my head with a scarf, I wasn't ashamed of my baldness because I know why it has happened many people don't know why they might have that. But it was surreal.
>
> **MB**: What was surreal? Could you explain that for me?
>
> **Sharon**: Well. Other people are getting on with so much and they don't know what I am going through you know. You look at girls passing with their long flowing hair, pregnant women and you never notice that before but suddenly those things it just completely changes. I now notice pregnant women and I seem to be seeing them everywhere now, your perspective of life changes.

Sharon's and Ebony's narratives suggested feelings of regret, feelings of

being robbed which were linked with loss of fertility, femininity and sexuality.

Sharon saw not having had a choice about storing eggs as a lost opportunity

given there were opportunities to do so, She mentioned this several times at

different stages in her story, at times becoming tearful. She talked about being

'blessed' to have had her daughter, especially as it was the pregnancy that

led to an early cancer diagnosis. However, that still did not take away the pain

of possibly never having children in the future. She articulated both the

physical and emotional disruption cancer caused on impacting future family life, highlighting what Bury describes as the relational impact of the illness on the self and social identity. Sharon's narratives also revealed how she coped with another kind of unexpected loss: alopecia (hair loss) and how having alopecia changed the way she viewed life. In losing her hair, she decided to take ownership and regain control over what the cancer was doing to her body image (by choosing to wear headscarves).

The use of the word 'ashamed' was interesting in relation to societal images of women, in which baldness can be viewed as unfeminine or associated with lesbianism. Her narratives suggested that knowing why she had her hair loss provided a basis for comfort, as well as establishing an evaluative dimension, to give legitimacy and justification to her altered body image. This is reflective of Bury's moral narrative in how she addressed altered relations of her physicality and society, brought about by the illness: she illustrated this by taking control of the physical alteration caused by the illness to reclaim her identity. Her narrative implies knowing why she was bald enabled her to recover her self-worth and her response justified the altered relations caused by cancer, what Hydén refers to as an 'active engagement', with her illness which counteracts the negativity of the illness and its effects. She presented a counter-narrative regarding the dominant imagery of women, in society and what is means to be feminine.

There was shock at the suddenness of being diagnosed with cancer for Sharon and for June, the perceived difficulties with the biopsy results. Both

women used the word 'blame' in their narratives; yet neither wanted to blame clinicians for not getting the processes right or where mistakes had been made. The unpreparedness narratives as well as the 'Do I have a story?' narratives suggest not wanting to turn against those who had saved their lives and gave consideration to what may have been reasons for the problems, 'staff shortage', 'heavy workload' (June), 'these things happen at times' (Sharon). However, Kahn's and Ebony's narratives presented a different perspective to June and Sharon when optimum cancer healthcare, their narratives suggested, failed them. Ebony's narrative account follows in the next section and Kahn's narrative is presented in Chapter Six, section 6.1.2.

5.1.2. Life's bad breaks

'Why me?' was not a phrase used by any of the participants when they were diagnosed with cancer, however instead for three participants (Ebony, Michael and Mary) the diagnosis was seen as something else that was another of life's blows to an already challenging life. Such philosophical views were also found in the studies of Henderson and Davies, (2003) and Nanton and Dale, (2011). Ebony's story represents a reflection of the journey of diagnosis, its treatment and how she continually 'lifted' herself in mind and spirit to cope with another adversity in her life. The diagnosis was unexpected but the emphasis in the narrative reflected dealing with yet another problem (cancer), but the experience was compounded by what she perceived as poor care and poor interactions with cancer healthcare professionals.

> **Ebony**: My first diagnosis was in 1998. I felt a lump under my left arm, I didn't think much about it but it didn't go away after 2 weeks. I was on

holiday in Jamaica at the time and I asked some older women and they said it was a cyst and not to worry.

MB: Okay.

Ebony: When I got back to London the lump was still there so I went to my GP who examined me but didn't say much, just told me I needed to go to the hospital.

MB: Did you ask the GP about it?

Ebony: Well yes but he just kept saying it was best to go the hospital for investigations. He didn't explain what those tests were. He kept mumbling, he wasn't clear and the time with him felt rushed.

MB: And what happened at the hospital?

Ebony: So I went to the hospital a week later to the breast clinic. No one told me what was happening. The nurse asked me if I knew why I was there and I said it was because I had a cyst. She never said anything to suggest it was more than that. No information was given to me. I was sent for a scan, no explanation about what to expect, what would happen. I was beginning to get concerned because of the lack of information and I had a lot of personal issues going on at the time, which just added to my stress.

MB: And these other issues were impacting on what was happening?

Ebony: Yes because when I returned from my holiday, my partner was given his results of tests he had and we were told he had kidney failure. That was scary. Here I was with this lump. I was hoping was just a cyst but not being told anything by doctors or nurses. He was due for more investigations and dialysis was now going to become part of our lives.

MB: So that must have been a very difficult time.

Ebony: Very difficult. I had to wait 2 weeks for my results. The total lack of support and lack of information from health professionals was awful and to top it all, they lost some of my results and they wanted to do the investigations again.

MB: How did that make you feel?

Ebony: Angry, very frustrated. How could I trust them? They did apologise but that was not relieving my anxiety.   Why would I go back there? But I had no choice. So I had the tests again and they told me I had breast cancer and they said I had triple negative breast cancer and that I had to have chemotherapy and surgery.

MB: That must have been a shock to you?

Ebony: Sort of. The way things were going at that time of my life with my partner, I just felt a bad vibe but still I didn't understand what was happening. What was this thing triple negative. There was no available information at that time about this. I learnt over the years that it is a common type of breast cancer in black women, which does not respond well to chemotherapy which is why surgery is almost always done. That was really a pretty awful period in my life.

Ebony's account represented Hydén's (1997) idea of disintegration of a person's world caused by illness. Ebony's story indicated how cancer was a life-changing event impacting on both her current and future life; she and her partner had been trying to start a family and were undergoing IVF investigations before her partner's diagnosis and now work was going to be difficult for her partner with his diagnosis of renal failure and compounded by the fact that she now had a diagnosis of breast cancer.

Her narrative, like June and Lorna in their narrative accounts, was reflective of her perceiving that the news regarding her symptoms was inevitably going to be bad (that is, being diagnosed with cancer), again reflective of Bury's (2001) contingent narrative in her narrative reflecting links between events which create the situation for the belief in the resulting outcome occurring. Ebony's story implies challenges with lack of information, problems with bureaucracy and presents her as being in receipt of sub-optimal care at that time. The narrative outlines her views of mismanagement, feeling let down, a lack of response to questions being asked, coupled with her partner also having a diagnosis of a life-threatening illness, creating a disrupted present and an uncertain future. Even though her narrative on the surface may reflect the notion of having to deal with yet 'another problem' it does, however, still typify the immense disruption chronic illness placed on her and her partner and

accords with Bury's (1991) notion of biographical disruption; everyday life activities, requires negotiations and living with unpredictability.

Lorna's narrative like that of other participants (Sara, Sharon, Kahn, Joseph, Ebony), also reflected the difficulties of family life caused by illness, but here as with Ebony, within a 'life's bad breaks framework'.

> **Lorna**: I was the main carer for daddy when he was diagnosed with Alzheimer's disease, which was about six months before I was told I had breast cancer. I was just getting into some kind of routine and I just thought what next? How will we cope?

Jennifer's narrative similarly presented her account of how as an individual she battled with illnesses and saw her diagnosis as yet another hurdle to climb.

> **Jennifer**: I have had hypertension for a number of years and at times it has made me quite ill, particularly causing some really bad headaches. Then about eight years ago I developed really severe pain in my left knee, to the point where I couldn't walk sometimes without aid. I don't drive and a big part of my job was obviously teaching the students in the hospital as well as at the university, so mobility was slowly becoming a problem. Work in general was becoming very problematic, very stressful and this was not helping my blood pressure. Eventually I had to have surgery and I was off work for months. During that time I really questioned whether I wanted to go back to work. I decided it would be better for me to take early retirement, which is what I did in August 2009. Best decision I thought and then five months later I was diagnosed with breast cancer. What's funny Marvelle, I regularly check my breasts and in October I had a mammogram, it was clear so I gave myself a holiday in November [not to do breast self examination that month]. In December I felt a lump and was diagnosed with breast cancer in January. Well I thought did I deserve this? But I'm not the sort to wallow in self pity. For quite some time I had to watch how much I did, was tired a lot, but I compensated for that.

Jennifer's narrative presented a different perspective on this sub-narrative in comparison to Lorna, but similar to Ebony; in terms of resistance to 'bad breaks'; in not 'allowing' the catalogue of illness events in her life, become a

central factor through which they live her lives. Jennifer also took a very pragmatic and philosophical view of breast cancer, which again reflects some defiance to 'life's bad breaks'.

> **Jennifer**: They [the breasts] have done their job, served their function, I breast-fed and if there is a choice between any sexual function of my breasts and having a mastectomy to live, well there is no debate.

In her narrative, Jennifer referred to having reconstructive surgery at the same time as the mastectomy surgery, suggesting that although she referred to breasts as being functional, they were an important part of her femininity. This aspect of her narrative reflects Bury's (2001) notion of moral narrative in regard to normalisation, of her wanting to keep her pre-illness identity intact, but she was open about her illness suggesting that although she wanted to retain her identity she was not hiding the illness; reflecting wanting to 'normalise' her illness within her daily life.

These three narrative accounts highlight Bury's (2001) contingent narrative in regard to the relational context in chronicity of illness and its interplay with everyday life activities. For example, as with Sharon's narrative framework of being 'unprepared for the diagnosis' in feeling out of control, here Lorna was also expressing a sense of out of controlness. Her focus was not on herself but her father and what would happen to him and the disruption to having had some order to his daily activities, the worry of how this might lead to some regression in his condition and the time taken to arrive at a point which enabled her to cope with daily life, cancer has now brought chaos to a finely balanced difficult life.

Ebony's narrative account went on to describe the treatment she received by the clinician when cancer re-occurred, again through a series of mishaps and delays, the 'bad breaks' of life which Ebony again strongly resists.

Ebony: Three years following my left mastectomy my right breast felt a bit lumpy, a bit stiff and I had a rash. I went to the GP and he told me there was nothing to worry about. I wanted to believe him because I couldn't contemplate having cancer again. But I still didn't feel right after 2 weeks so I went back to the GP and he told me I was allergic to something and gave me a prescription for ibruphen cream. That helped with the rash a little but my breast still felt lumpy and again I returned to the GP. He referred me to the hospital. Considering my history you would have thought I would have been seen as an emergency but there was a delay in being seen by the consultant. I was seen at the hospital, two weeks after being referred. I was told the breast was very glandular which was why it felt lumpy. I had a mammogram, which showed something suspicious and a biopsy confirmed I did have breast cancer.

MB: That must have been devastating news for you and your partner?

Ebony: I just felt numb. All I could think of was going through the nightmare again. It was also at that time, I discovered I was pregnant.

MB: How did you feel about that?

Ebony: I was on an emotional rollercoaster. I was told it was not possible to get pregnant after I had had my treatment and I saw this as a blessing but such bad timing. My partner's illness had deteriorated severely and here I was with a pregnancy and not sure what to do now I had this cancer back. We hadn't had children and we did want children.

MB: What did the doctors do to help?

Ebony: I was not happy with my treatment. I kept asking questions I guess I was being seen as challenging and I was being seen as aggressive and argumentative. A trouble-maker.

MB: Why was that do you think?

Ebony: I think because I kept asking questions. I was getting conflicting answers and being made to feel small. I did feel there was some racism, just in the way I was spoken to, how I was treated. This was my life and I wanted answers. I wanted to give the pregnancy a chance. I was so angry with them, the cancer. It was now in my right

breast and under my right arm. Anyway nature took its course and I lost the pregnancy when I was four months pregnant and my partner died 5 months later.

Ebony's narrative straddles other narrative themes related to communication, 'race' and ethnicity, highlighting the interrelations and inter-connectedness within and between personal narratives and the intersectional ties of 'race', gender and illness. Her narrative described how she perceived she was depicted by health professionals when she used words such as 'trouble-maker' and 'aggressive'.

In reliving her diagnosis, her account was reflective of heightened emotions, of anger at what had happened. Her narrative suggested having to be strong during the time of her diagnosis and treatment as she was also supporting her partner and having to battle to achieve what she wanted and needed. She represented the tension of women in control in a 'bad breaks' situation, who nevertheless themselves needed support which was not readily available.

Both Ebony's and Jennifer's narratives present very strong counter-narratives to resisting 'succumbing' to feelings of dejection, but instead took steps to gain some control of what was happening; Jennifer, by 'not one to wallow in self pity, watch how much I did' and Ebony, 'I kept asking questions'.

As part of this sub-narrative, fertility and its relationship with femininity and womanhood was a significant feature of stories for two participants (Ebony, aged 34 years, in her 'bad breaks' narratives and as we have already seen, Sharon, aged 32 years at the time of diagnosis in her 'unprepared' narrative). The other female participants, who had cancer, did not have fertility as part of

their narrative and this might be explained because the cancer was not gynaecological, or they had not received chemotherapy or radiotherapy, or were menopausal. Michael, the only male with a cancer diagnosis, did not discuss fertility in his narrative, but he did focus on sexuality and the loss of masculinity due to erectile dysfunction caused by the prostatectomy and the effects of hormonal drugs.

Ebony's narrative outlined the loss of fertility and the unexpected joy of a pregnancy only to be compromised by the re-emergence of cancer, which shattered the possibility of having a family. Both Ebony's 'bad breaks' and Sharon's 'unprepared narrative' featured loss as a significant element; however, Sharon did not feel isolated in her loss, she found strength in support from family, her church and other patients. As in other 'unprepared' narratives, new or newly accessed resources were narrated. Ebony did not have such a network; she was separated geographically from her family and had few close friends having relocated at the time she was diagnosed. However, a number years after her double mastectomy, she discovered a charity of which she says, "it gave me back my life". She alluded to this further in her narrative, of regaining her confidence and how the charity lessened her feelings of isolation; because it was a charity for black women who had breast cancer, there was a shared understanding of experiences.

5.1.3 Summary

The narratives so far presented have highlighted a number of factors: lack of information, delays in diagnosis and lack of support from professionals as difficult elements of participants' cancer experiences. Positive experiences of

being listened to, feeling respected, were important features which some participants, including Mary, Sharon and Ngozi as well as June, alluded to in their narratives. Ebony's narrative presented a different experience, of lack of respect by clinicians towards her which impacted on trusting clinicians and led to her, feeling powerless and vulnerable as her survivorship was in the hands of the clinician.

A striking feature of all those diagnosed with cancer was defiance of the disease and determination to get on with their lives, the importance of not having the illness dictate or hinder their own futures. No participant wanted to wallow in their diagnosis or hide behind it. The narratives themselves seemed to act in this way for participants, as they gave 'witness' to the evolving impact and challenges the narrators faced in coping with life-changing events created by cancer.

5.2 Narratives of religion, spirituality and faith

Religion and spirituality are deeply entrenched within the fabric of the culture of the black community. For many black families, churchgoing and considering the meaning of pastoral sermons is commonplace. The church is a social network in which positions people hold can form part of their identity and chronic illness such as cancer can compromise and threaten that identity. However, religion and spirituality can also be an immeasurable force in coping with cancer.

Needing to find an inner strength to cope with the uncertainty of a life-threatening condition such as cancer, people draw on what might be

considered a higher power, be that religion, spirituality or a deepening of their faith. With the exception of Kahn, who stated he was an atheist, all other participants found tremendous solace in either their religion, which they practised, or, as in the case of Sara's father, the diagnosis led to a re-connection to his faith. For five participants their narratives implied the diagnosis was a test of their faith, their belief in the power of God, which suggests a moral imperative to their behaviour. The thematic sub-narratives developed from their stories were: How deep is my faith: divine power versus accepting medical interventions and putting my life in the hands of God: the power of prayer.

5.2.1 How deep is my faith; divine power versus accepting medical interventions

Some narratives (Ngozi, Sara) suggested a conflict existed between belief in God and accepting cancer treatment or attending cancer screening services. Ngozi reflected on herself in comparison to what she perceived as the behaviour of Nigerian Pentecostal worshippers.

> **Ngozi**: I'm a Christian, and I've got really strong faith, absolutely, believe 100% in the Lord, and I'm Pentecostal. My diagnosis was opportunistic. [Ngozi was undergoing investigations prior to having gastric band surgery to help with weight loss when renal cancer was discovered] That was God's miracle for me. For me, the way I see it after the Lord has actually caused it to be exposed [the cancer], I'm not still expecting him to come down from heaven to take out the cancer. I just was appreciative that it was exposed and I got rid of it. But, for lots of people in the Pentecostal faith, particularly Nigerian, you have an operation, you're saying God can't do it, and they believe in healing so even accepting surgery, for some people, they would deny. I'd call it denial because it's there if it's been diagnosed, I think that's God's grace.

> **MB**: So would you say that the belief may affect people's decision to go for screening for cancer?

Ngozi: Sure. For many, many people, they wouldn't engage with the service [screening] to start with because they would pray against it, end of. Not many of us have regular checks, not many of us actually believe in the GP at all, you understand, cause when we are ill, we speak a word of faith, a word of prayer, and we believe that the Lord will deal with it. So much so, to a point that, yes, I don't think people from where I come from really access the services that are available to them because it is seen as giving up and it's a downward spiral from there. So you just need to stand on your own feet and be strong. You must have faith. So if it's a niggling pain you curse it, and you keep on cursing it.

MB: And in your experience, this is a common practice?

Ngozi: The way I've experienced things, with regard to church, is the fact that many of us, appropriate pastor's to be God. So anything they say is what God is saying, and they lose like you said themselves, and they hang on to the word of their pastor without questioning and I think it's a very dangerous thing not to question, and I'm not saying question the word of God, but find God yourself. And another thing that I have noticed operates in the community, and in the church, is the fact that when you actually say someone from the family's got cancer, it's kind of it's like a curse. You want to show the world that your family's blessed and blessings and prosperity, good health. So suddenly we have cancer in the family, we must not let anybody know or hear that we have a curse in the family. God forbid, not in our family.

MB: So are you saying there is a cultural issue at play as well?

Ngozi: It's culturally an issue, yes, and it is religious. In the religious bit it's like maybe they've sinned and that's where cancer's crept in. It was a sin, the hedge is broken. The serpent can seep in, so maybe there's sin, or maybe there's lack of faith, again, this person's supposed to be a strong person, but that happened, because even if they had the faith, even if it was cancer, then they'd be able to pray to it. And what happens towards the end, and this is not, I'm not speaking about this lightly in any way, death is a heavy blow, but what happens to the end with some of the Christians who have refused treatment, they've been, umm, kind of looked at as martyrs. They've stood their grounds in the faith. They refuse it because of God and they die and they go to heaven. It's like I live, I die, I die for God, which is individual choice, but the way I see it I beg to differ a bit, the fact that God provides doctors, provides us with herbs to get better. I think the facilities God has given us need to be tapped into and I see it as a blessing.

Ngozi's accounts suggest a very strong, almost inseparable link between culture and religion. Her narrative also made a relational link between religion

and access to cancer services particularly in reference to screening as well as accepting treatment. Her story outlined how perceptions of a loss of faith or faith not being 'deep enough', in cases of illness, can impact on acceptance of cancer services. It suggested that a significant contribution to how people act in cases of ill health is in the individual's perceived level and depth of belief in God. Her account implies having a cancer diagnosis seemingly places the individual and their family in isolation from the community for fear of being seen as having sinned in the eyes of God.

Ngozi's perception of individuals' reactions to ill-health is once more an example of Bury's (2001) contingent narratives: it reflects the interconnections between, culture, religion and illness behaviour. Her narrative articulated how the fear of social reactions to having cancer is embedded, even entrenched, within those who are in the Nigerian Pentecostal community. It is interesting how she presented a counter narrative to her perception of other Nigerian Pentecostal worshippers and that she speaks candidly and openly about her own diagnosis, not considering herself to be 'cursed' or viewing the cancer as a punishment for any previous transgression. There was, however, some family conflict as she went on to explain:

> **MB**: You mentioned earlier your sister is a Pastor, how did that make you feel when you to choose to have treatment?
>
> **Ngozi**: Sisters you don't choose; don't worry, I love her. She supported me in the end, I love her to bits, but she's was telling me, oh, don't have the operation, faith it, and I was thinking to myself I'm not listening to you, I'm never listening to you when it comes to medical, because can't you see my miracle in this, then you don't understand that is the powe of God.

Ngozi's narrative presented tensions between her and her sister who is a

Pentecostal pastor and her account implies she is seen to be going against their belief. Both Ngozi and her sister are educated women and the social positioning of both women is middle class, yet their individual behaviour in relation to illness in the context of their religious beliefs is diametrically opposed. Her narrative suggests she is sitting outside the social representation she articulated in her experience of Nigerian Pentecostal followers, illustrating that although culture and religion are intertwined, it is complex and individuals can ultimately make their choices.

Ngozi presents as being independent and she took the view that rather than being passive about her illness she takes her own steps, and interprets her religion from the perspective that technological developments and advancement in treatments are there by God and hence should be used. Her account implies the diagnosis led to what Bury (2001) refers to as an examination of her belief and personal circumstances. She took an active decision to have treatment believing it was provided by God and hence having surgery was not against her faith, but rather the existence of medical developments attested to God's power. Her narrative suggests her acceptance has placed her in some family conflict. Nevertheless, her story implies that the bond between her and her sister had not been broken. She articulates weighing up her options with the guidance of her faith and a strong belief that developments are miracles of God and there to be used.

Ngozi's narrative suggests the power of the pastor is perceived, though not by her, as synonymous with God, which places a great deal of influence in the hands of the preacher, making it difficult for some parishioners to go against

the word of the pastor for fear of retribution. Other participants' narrative accounts also focussed on the 'authority' of the pastors, but not in the same negative way as Ngozi. Sharon found solace in her pastor's interpretation of a piece of scripture she felt she had been 'directed to' read by God. Sharon is a Baptist.

> **Sharon**: Going through treatment, you know God gave me another scripture that prepared me for treatment and it was Isaiah, Chapter 53 and 1 and 2 and it says when you go through the waters I will be with you and when you go through the floods they will over flow you and you will not be burnt or not scorched and again the water theme was all entwined there so I really took it personally. That was the point where I was unsure as to whether I should be treated and my pastor interprets it for me and he said some people get through their healing in the beginning but some people have to go through and you know my portion (situation) was to go through and those are the words I hold onto. I know it was never about me and always about Him (God).

Unlike Ngozi's narrative, which portrayed Nigerian Pentecostal worshippers as having to struggle against their belief and acceptance of medical interventions, Sharon's story of her experience with her pastor helped with her indecision and she was not constrained by having to think she would be failing in her beliefs if she accepted treatment. Other participants (Mary, Jennifer, June, Cheryl, Joseph) reflected Sharon's narrative on how the pastor's power was not one that took away independence in personal decision-making. Sharon's interpretation of the meaning from the scripture she holds onto is a 'cushion' for coping and it becomes a basis for her support through treatment and to retain a positive outlook. Her narrative implies having the belief in the power of 'knowing' God will make things right, giving her a sense of peace.

5.2.2 Putting my life in the hands of God; The power of prayer

This sub-narrative theme reflected how many of the narrators saw prayer as making close connections to God and through prayer, saw God as controlling all decisions about their care and recovery. Mary, like Ngozi, was a Pentecostal and told a story which also implied that religion was deeply important to her. Like Michael, June, Lorna, Jennifer, Ngozi and Sharon, she believed that God would get them through the treatment. Mary's account suggests she viewed her experience of survivorship as a living testimony to God. She presents in her narrative the drive to give something back, which fuels her openness about her illness.

> **Mary**: Prayer works Marvelle. Some weeks after the chemotherapy I had a scan and it showed metastases in my uterus and liver and the doctor said we are going to have to be more aggressive with the chemotherapy. I was already tired out from the first lot and I said no more, no more. I just couldn't take it. I just said no. The doctor said to go home and think about it. My husband was with me and he said let's go home and pray. We told the pastor and friends and we asked them to pray. Two weeks later I went back and they wanted to do another scan. I didn't really like having scans but had it anyway. Marvelle, the doctors were confused. They could not believe what was on the scan. He called another doctor and compared the last scan result with results he had from this one and they could not see any tumour. They could not explain it. To me that was the power of prayer. God was working for me. This is why I talk to people Marvelle, to show cancer is not always a death sentence and God is always there.

Her narrative here is an interesting interconnection between what she perceives as the power of prayer and the outcome of medical intervention. Her account reflects Bury's (2001) moral narrative in how Mary evaluates her positive outcome and the unexplained ambiguities of her scan results against the background of her religious beliefs.

Like Mary, Jennifer eloquently presented in her narrative what she valued as the collective power of prayer, in lifting her spirits, rather than the physical effects of prayer. Her narrative refers to the feeling of unified energy in knowing people collectively in unison thinking positively about her.

> **MB**: You said you have a philosophical approach so I am just wondering does that lend itself to spirituality?
>
> **Jennifer**: Oh gosh yes, there is no doubt about the spirituality element of it because I don't feel that I would probably have had as good a recovery or have felt as positive and have a positive outlook in terms of my future if it had not been an element of putting it in the hands of God shall we say because from the moment I sort of told family and friends and I didn't make a big secret about it I told everybody, everybody knew and it was positive affirmation, sort of the universe, God, prayers, all around and I have had overwhelming support from a variety of people part of which has been prayer, erm, and when I have been in my weaker moments (laughs) I have done some on my own behalf. But I didn't just turn to prayer because I had a condition and I felt I needed to do it, I do believe and I do sort of go to church and I am a regular church goer and that sort of thing so it just meant that I injected a little bit more effort on my own behalf in the hope that it would be received and well answered and get divine inspiration and intervention as part and parcel of the whole process but without doubt and even with extended family who are abroad who can't be physically here to do things when you need a helping hand around the house and that sort of thing have said they will be praying or they have said special prayers. I used to belong to a church group where I was a member of the choir and once they knew they have been adding their collective prayers and that sort of thing and whether you chose to believe or not, all that is wonderfully nurturing and nourishes the soul and I think that has been helpful to know that has existed.

Jennifer's account again can be referred to Bury's (2001) contingent narratives. It indicated how believing in the collective powerfulness of prayer was her means of coping with the adversity of cancer and its treatment. Jennifer's account illustrated the psychological and emotional benefits of believing in others having positive thoughts and actions through prayer which were focussed on her. However, she does not solely rely on the grace of

others and her actions are suggestive of representing Bury's (2001) moral

narrative also within her story when she comments: 'When I have been in my

weaker moments [laughs] I have done some on my own', suggesting she

increased praying in her own capacity which added in her mind to the

collective impact of the power of prayer.

Biblical metaphors were used by some narrators (Jennifer, Mary, Michael)

and Sharon's narrative like those participants, used quite powerful metaphors

in her descriptions of seeing the power in prayer. Her narrative is presented

because it contained relational links with incidental events and 'receiving

messages' from God, which some other narratives allude to.

> **Sharon**: I am a Christian and this is a strong foundation of how I live my life and of course when I was diagnosed with lymphoma it was foremost really. Actually, the morning of the day that I went in and when I first probably used the word cancer I had a dream and in essence I didn't know what it meant at the time but in time it became clear I would overcome. There was this tsunami type wave and I was on a sea front and it came and there was this wall and because of the wall I was able to get over the wall and I was safe and when I went into the house it was like we were on some camp or something and when I went into the house where we were staying I had heard that this one had died and that one had died and I didn't even understand at that point what I had escaped from and I didn't think too much of it at the time but afterwards when I had the bone marrow biopsy I came home and a scripture verse in particular came to me that when the enemy comes in like a flood the Lord will raise up and stand against him and that's what I held onto.
>
> **MB**: So what did that mean to you?
>
> **Sharon**: To me it was almost a vision of the perseverance and what is actually coming at the end is me coming over that. Not too long after that dream, I heard of two people who had died from cancer so it came true as well that there will be people who would have died who would not have survived and I had heard of more as well. Another thing one day, I think they had just told me, probably the same day they told me about the cancer; I was lying down after the bone marrow biopsy and it is quite a painful procedure and I was looking out of the window and I saw the name of the window blind was defiant so God was telling me

how my case was going to be so and it has been you know, would defy what the doctors think and those are the two things I really hold onto. The source of my strength from God really is undeniable. I felt at peace when I started my treatment. The doctors put me at ease and I believed I was in good hands.

MB: That's quite powerful, really very powerful.

Sharon: Yes and as for my transplant I was very blessed and lucky to find a donor in my sibling because I know if I didn't have a sibling it would probably be, have been impossible you know with my sort of mix and background it would be very difficult, so again I attest that to God you know.

Symbolic inferences in her narrative were commonly found in other participants' narratives too (Ngozi, Mary) and were used as a basis for demonstrating God's existence in their lives. Her narrative suggests faith and belief provided a foundation for giving her a sense of peace and provided a 'cloak' of hope around her. How illness narratives are shaped by symbolism is not explicitly accounted for in Bury's (2001) and Hydén's (2001) frameworks, but there is a suggestion of an evaluative dimension to her narrative, which partially reflects Bury's (2001) moral narrative type.

The belief that prayer can be a commanding force which challenges medical opinion was a feature in narratives such as Mary and Sharon, but Joseph's narrative relates the power of prayer not in curing cancer but of increasing longevity of life. His narrative, spoke of the strength his wife received from their faith and prayer and how they kept him strong. They were both Baptist and he believed the love of the family and the strong beliefs of his wife defied what the doctors said about her prognosis.

Joseph: The pastor would come to our home most Sunday afternoons and would read scripture which Rosie loved and that gave both of us strength. Our children were fantastic, we were never alone. The ones that lived close by took turns to spend nights with us and I am sure all

of that was important to Rosie and kept her going. The doctors said she had three months but she stayed with us for nine months. Those times were precious.

As with the narrative accounts of Mary and Jennifer, Sharon's and Joseph's narratives represent another aspect of Bury's (2001) contingent narrative illustrating how religious beliefs can shape the framing of the narrative accounts. Bury (2001) discusses how culture can shape the narrative and what these narratives have presented is strongly determined by one of the primary elements of culture, that is, religious beliefs. Symbolism articulated in Sharon's narrative was seen across other narratives. In Joseph's case, the 'family of faith' is articulated in the narrative in association of the pastor visiting the home, the presence of their children in the home, all of which gave Rosie life.

5.2.3 Summary

Religion was deeply important in giving strength, aiding in coping with and managing treatment. The complexity of individual action versus that potential action to be in conflict with the pastor's 'message' can create challenges with religious practice and acceptance by others within the church. The power of prayer seemed to have been of immeasurable value to participants. Individual behaviour and response to illness provides a complicated interplay between religion and culture. Miracle was a word repeatedly used by narrators. Regardless of profession or the level of education the participant had, being diagnosed with cancer led to narrators searching for meaning and value of life, re-affirming belief in something higher than themselves and seeking God's guidance in or aside from the work of the clinicians. Illness narratives frameworks such as Hydén's (1997) and Bury's (2001) could expand to

accommodate gaining a deeper understanding of and meaning placed on religion in how it shapes the narrative.

5.3 Conclusion

Having summarised the narrative themes, here I contextualise those summaries in relation to how they address the research questions. In particular, the narratives themes analysed in this chapter, provided insights into what affected narrators' experiences of cancer services, how culture, ethnicity and societal constructs influenced the experiences, coping strategies adopted to manage the effects of treatment and long-term consequences of cancer and the treatment and reactions to the diagnosis of cancer. Furthermore, the narrative themes illustrated the impact of the diagnosis on relationships with family, friends, and their communities.

Culture, ethnicity and 'race' formed a distinct narrative theme from the narratives and are presented in Chapter Six. However, they are constructs which straddle across the narratives in various ways and therefore there is some overlap between this narrative theme and the themes explored in this chapter. In particular, narratives appeared to articulate associations between factors that influenced narrators' experiences with culture and ethnicity, and how they coped with the diagnosis and treatment. In the narrative theme 'reliving the diagnosis', positive experiences related to openness, truthfulness, transparency, and feeling there was an interest in them as a person. Being ignored, being cast as an aggressor, lack of consideration of ethnicity, and not

acknowledging their individuality were features which negatively impacted on some narrator's cancer experience.

Not only did the experiences with healthcare professionals impact on the narrators' abilities to cope with the diagnosis and treatment, there was also an articulated presence within their stories of an inner strength, drawing on intangible support from religion and spirituality and tangible foundations which included family, other patients and the black voluntary sector to meet both cultural and personal needs. Drawing on these supports, the narratives suggested that regardless of whether the narrator perceived they were in receipt of good or bad care, their tenacity and their pragmatic commitment to resistance kept them from falling into a negative mindset and prevented cancer becoming a controlling force in their lives.

Religion and spirituality are highly salient closely intertwined within the UK African and African-Caribbean community. Hence their value in illness as a supportive cloak was unsurprising. What was explicitly different and potentially linked to cultural differences not previously uncovered in previous research, was the power of pastors in influencing decision-making in relation to health-seeking behaviour. This is discussed further in Chapter Seven. Narratives demonstrated how religion can shape the way the narrative is told with biblical metaphors providing imagery within stories, making a point more vivid and adding to emphasis to particular parts of stories.

How narrators presented the impact of the diagnosis of cancer on the family and wider community, illustrated some distinct cultural differences. The African-Caribbean and Ghanaian narrators shared similar perspectives on

how their communities react to cancer. There was trepidation about the word 'cancer', but no fear of being ostracised from the community, which was strongly suggested by the Nigerian narrator.

The value of using a narrative approach was borne out by the revealing of thematic elements within narratives that related to: the cultural context of breast self-examination, the lack of culturally appropriate imagery related to cancer, narratives of carers, self-blame and self-examination. These were unexpected themes that emerged through the research process of enabling storytelling, and the analytic process of paying attention to extended narrative responses. Hence, taking a narrative approach was valuable in reaching a depth of understanding of the complexities and interconnections between the self and society, which possibly may not have been attained by other forms of qualitative research.

The narratives suggested areas for research exploration and expansion which could prove useful in developing Bury's (2001) and Hydén's (1997) typologies, in particularly around issues of biblical symbolism and how religion frames the narratives. These issues are often significant in narratives which interrelate ethnicity and culture and coping with illness.

CHAPTER 6: FINDINGS, PART II: THE NARRATIVES ON COMMUNICATION AND ETHNICITY

6.0 Introduction

Consistent with the presentation of the narrative themes presented in Chapter Five, this chapter also uses exemplar extracts with the intention of demonstrating the progression of how narrative themes were formed. The narrative themes presented in this chapter are; 'healthcare professional-patient communication on cancer', 'screening' and 'culture, ethnicity and race'.

6.1 Narratives of healthcare professional-patient communication on cancer

Communication is a complex phenomenon involving many factors such as lexicon, syntax, dialect, facial expression and intonations, which interplay and are interwoven with culture, race, ethnicity, gender and education. When communication is placed in the context of a life-changing diagnosis such as cancer, it takes on a critical dimension and, if poorly conducted, can have a negative impact on uptake of treatment options, on symptom management, on the psychosocial illness experience and ultimately on overall quality of care.

Communication between the narrators and healthcare professionals was a narrative theme found in all participants' narratives. Exemplars represent the different impact and affect both positive and negative communication had on participants. The experiences were captured under three sub-narratives: Can I ask a question? Acknowledging me: I do have feelings and, Almost there: but not quite getting communication right.

6.1.1 Can I ask a question?

This was an aspect that appeared frequently as a narrative theme in the narrators' narratives. The narratives reflected the challenges of not knowing what to ask, how to ask the right question and not feeling able to ask the clinician for clarification of medical terminology.

Jennifer's story articulates concerns also found with three other participants (Cheryl, Mary, June) regarding assumptions made by healthcare professionals about the knowledge they would have because of their health background. The narrative accounts of these three participants also suggest the pressure of clinical time in clinician-patient consultation, which impacted on participants feeling able to ask questions.

> **MB**: How was the diagnosis and treatment explained to you?
>
> **Jennifer**: It was okay, but I think it's about never assuming what another person might or might not know because sometimes assumptions can be made and there were a couple of times where I had to ask what does that mean specifically and I think it was because I did a lot of reading and I knew quite a bit and it may have been assumed that I knew everything and no person can know everything about every subject and that is why you have experts in a particular field yes, but I asked and I got the information but that was because I asked for it.
>
> **MB**: So do you think in terms of communication it is about trying to make sure that you are given an opportunity to question?
>
> **Jennifer:** Yes it's getting the balance right, that you don't talk down to people or they don't feel that they have been spoken down to but still giving them the information whether they want it or not. If you give it to them you know they have it rather than assuming that they've got it. But that is down to the length of consultation because in order to be sure that the person, the patient, is receiving the right information and that the consultation has gone well needs time and very often time is the negative element or the lack of time in that how many times do you tell a person to make sure they have got it when you have got only ten minutes to see every patient and for one person it may take eight minutes and for another it may take twenty eight minutes but an

individual cannot give consent or be a participant in the process if they don't understand so sometimes it needs as long as it needs.

MB: Do you think as a health professional, you were confident in creating the opportunity to ask questions?

Jennifer: Yes quite but I guess from a lay person's perspective asking questions or knowing what to ask might not be so easy if the doctor has not created an environment which allows a patient to feel comfortable to ask questions.

Jennifer reflected in her narrative on her former professional background as a health academic and her familiarity with the NHS system, suggesting that gave her confidence not only to ask questions, but also how to access information, which meant the consultation was more productive and purposeful. In the accounts of both Jennifer's and June's narrative accounts, it was implied that clinicians made assumptions about their tacit knowledge which they link to having health backgrounds. Jennifer was a midwifery lecturer and June a health visitor, but neither had experience of cancer and therefore they needed to understand the treatment regime and its effects. They suggested clinicians used medical terminology in relation to cancer treatment but did not discuss in detail until asked, yet their informational needs needed to be met, just like others unfamiliar with healthcare processes and practices.

Jennifer's narrative suggested how important it was for clinicians to invest time in explaining what will happen, not to rush consultations and to outline what the patient may expect during their treatment. However, her experience of the NHS is evident in knowing consultation time is pressurised and unless a

patient is able to be reasonably forthright, questioning may be difficult. Her

narrative widened beyond herself to consider others, thus indicating a

collectivism of the illness experience, reflecting Hydén's (1997) perspective on

how the individual's experience can encompass a collective experience; in

doing so, there is a sense of a social context to her narrative.

Positionality is of interest in this part of Jennifer's narrative. She appears to be

both with ("very often time is the negative element or the lack of time") and

against ("I had to ask what does that mean specifically") healthcare

professionals, illustrating for the individual the complexities of professional

and personal identities in reflecting in the context of an illness. In such

complexity, Jennifer does and does not counter the medical narrative, but

seems to use her 'insider' knowledge to counter the medical narrative from

'within'; in essence, she acknowledges that clinicians need to be better skilled

at communication, but also recognises that clinicians do not always create the

right environment or encourage patients to ask questions.

Some patients might attribute power to an individual based on that person's

position. Sara's narrative account about her elderly father implied such

behaviour.

> **Sara:** The doctors, bless dem [them], they didn't have the time, you
> know, that is my impression, but in Dad's case, I had to assert myself
> because we're talking the big C here. I went to most of his hospital
> appointments with him and dad would sit there and he just did not ask,
> it's just really strange because when we were growing up Dad only had
> to look and say something and then you know you're off and you're
> doing it, you know, but when it comes to the health professionals, I
> don't know whether they've blown his head with science or something,
> but he just would not ask, and I get the impression, talking to him,
> when we cum [come] back home, he said 'so wat dat bout, wa dem

sem ' [what was that all about, what did they say], he don't know what they're talking about to know to ask questions and I had to ask, because when they were saying that they were going to do, umm, you know a hemicolectomy, you know.

MB: You had to explain what that was to your father?

Sara: I could not believe what I heard when they said they were going to do a hemicolectomy, and they were going to let him go out [of the consulting room] and not explain. So I said to the doctor, well, could you explain, I know you're going to remove part of the bowel, but could you just explain to Dad how much of the bowel, and he [her father] got really frightened den [then]. I don't know, with the doctors, but, I think maybe they've divorced themselves from you know getting down to the level of the patient sometimes. That was my experience. But having said that, the doctor was really nice and I got the information I need because I asked, but I was thinking, if I wasn't there I dread to think what would have happened.

Her account suggests her father's realisation of the seriousness of his situation appeared to bring to the fore his own mortality, but that medical communication without her mediation would have given a very different message. Difficulty with medical jargon was also part of Michael's narrative.

Michael: They were okay, but me never really understand some of the words. He did give me a leaflet. When I got home I call my sister who is a nurse in cancer. She made me feel much better. She would come with me to most of my appointments which was a great help.

Sara's father's experience, like Michael's, depicted the critical importance of social and family support to grapple with managing both the consequences of cancer and untangling medical information. Michael's narrative also reflects what Hydén (1997) suggests about illness, in which illness can become contextualised into daily talk. In his narrative, Michael frequently spoke about his sister and their interactions regarding his illness and treatment and how that helped with encouragement, lessening his anxiety and continually being

positive about his prognosis. Both Michael's and Sara's narratives are reflective of medical narratives which point to clinicians' lack of communicative engagement with patients, which has the potential to leave the patient with either greater uncertainty as in the case of Michael or misunderstanding as observed in Sara's story.

Like Jennifer and June, Sara's narrative suggested she was able to use her healthcare experience to ask questions on behalf of her father and she reflects how difficult it must be for patients who do not have access to such support from family members and therefore how much more challenging doctor-patient consultations surrounding cancer must be, particularly for black elders.

These narratives suggest enabling partnership working between the narrator and the clinician requires the clinician to create an environment which encourages dialogue. This is of importance when treatment is going to be particularly intrusive; for example the women who had mastectomies (Ebony, Jennifer, Lorna, June), Sara's father who had a colostomy. These assaults on the body and the damage it creates to self-identity, requires phenomenal psychological adjustment, warranting clinician time to explore anxieties, fears, acceptance as well as any relationship problems. Adjustments in the face of such adversity impacts on the ability to adapt and adaption can be reflected in how, as Bury (2001) suggests, the individual normalises the illness within their lifestyle.

Cultural differences between the clinician and narrator can affect the interpretation and meaning of words used as Sara's, Ngozi's and Kahn's

narrative accounts outlined. In the case of words such as 'growth',

'inoffensive', 'all clear', the narratives suggested the creation of confusion due

to lack of clarity in their meanings. In Sara's narrative clarifying meaning was

an emotionally draining experience.

> **Sara**: When Dad went to see the doctor after getting the colonoscopy result and then biopsy and everything, went to see the doctor, so he'd gone home and everything and so I rang him later and I said Dad, you went and had the results, so how things go then? There's me thinking oh well he's just going to say its okay. He go, 'oh dem si me have sum ding him si growth' [they said I had something, he said a growth] and you know and I tell you I nearly dropped the phone and I had to say right Dad, okay, right, I've got to come, I say I'm going to come and see you this evening, okay, I'm coming soon, I'm coming yeah, don't worry, I'm coming. I left work because I could not concentrate because I think cancer, cancer, cancer, when I've gone over there [her father's home] he didn't understand, he goes 'no, no, dem si is a growth', [they said it is a growth] and say he's going to have to have it cut out, and so on, but I had to sort of explain to him to let him realize that the growth is cancer and so on. I asked did they say what it was and he just casually sort of said they mentioned cancer but Marvelle it was obvious dad did not understand the growth was a cancer growth.

Her narrative suggested there was confusion and lack of understanding by

her father that 'growth' and 'cancer' had an association. Sara's account

suggests how lack of clarity due to limited discussion or time taken by

clinicians to provide explanations led to potential misunderstanding. Sara's

story suggests her father believed that the growth was a minor problem and

the simple operation required to remove it belied the seriousness of the

situation, which is what Sara understood. Her reference to me, "but Marvelle,

it was obvious" in her story reflects several factors; the inclusiveness and

dialogic nature of the narrative and recognition of my position as both a health

academic and health professional. Sara's narrative reflected fear and anxiety.

Her account implied that these emotions were heightened by the fact that she

was a senior nurse and therefore had insight into the health challenges her father was going to face. Her story illustrates Hydén's (1997) illness as narrative as it depicts the construction of the illness world, one in which she made sense of symptoms and the impending struggle her father would encounter with the treatment.

Clinicians actions and reactions to being questioned, particularly on a difficult diagnosis such as cancer by patients or significant others of patients, can create diametrically opposed responses; either increased negative tensions or increasing trust and reducing stress. Kahn's and Ebony's narratives suggested that doctors can be reluctant to answer when questioned, as Ebony illustrated in the sub-narrative 'life's bad breaks' (p.170). Similarly, Kahn's narrative, in the sub-narrative 'acknowledging me: I do have feelings'; (p.200) depicts the same problem as Ebony.

> **Kahn:** I tried to ask her some questions but she had to go to a meeting at which point I turned around to her and said as far as I was concerned my wife's medical needs that she no longer benefitted my wife in terms of her medical needs.

When faced with life-changing treatment, trust in the clinician's judgement and decisions regarding the best treatment option is paramount. Jennifer's account provides an atypical view of how she referred to trusting the oncologist, especially considering she was a highly experienced health professional.

> **Jennifer**: I never saw a picture of my mammogram on the screen to say this is what it is, so if I really wanted to be difficult and I hadn't felt anything or I didn't have a belief in the system I could say they stole my breast because they didn't show me and I didn't see what they were looking at (laughing).

Although we laughed together when she made this point, there is an implied seriousness to this part of her story. When considering major life changing surgery such as a mastectomy and the ensuing potential physical, emotional and psychological consequences, which can be immense, having trust and belief in the clinician to make the right decision is fundamental and therefore sharing information with the patient is critical.

The narratives in this subsection have highlighted issues surrounding communication challenges and narrators' responses to resisting such challenges or seeking out sources of support which helped to fill the vacuum created by lack of information or lack of details provided. Doctor-patient communication is fundamental in shaping relationships between both players, but also to instil confidence and trust in how the patient will be able to consider restoration or emerge with a new self-identity they wish to use in engaging with the wider social world. Such behaviour reflects Bury's (1997) moral contingent in regards to how the individual will justify their changes in identity to as a consequence of cancer, for which they had no control over its development.

6.1.2 Acknowledging me: I do have feelings

Some narratives expressed that clinicians, whether intentionally or unconsciously, created an environment within the consultation, which led the narrators' presenting accounts of their feelings not always being considered. Lorna's, Ebony's and Joseph's narratives all suggested negative experiences of these kinds at times with clinicians, but Kahn's narrative was the most

extreme, perhaps because of the temporal and interpersonal distance it became easier to articulate than if it were an account tied solely to the self.

MB: Could you describe the care your wife received?

Kahn: Well my wife when she was diagnosed with breast cancer she had a really good oncologist, an elderly woman who she really got on very well with and felt very confident. She retired and a new oncologist was appointed now my wife told me and she told all our friends and families that she was basically terrified of her oncologist. Her oncologist was uncaring, unfeeling, wasn't interested in how she felt, wasn't interested in anything she had to say. My wife who for her it was very unusual for her to say this about anyone any to criticise anyone and she said her oncologist made her feel like she had trodden in something and you know, when my wife was terminally ill I decided to take time off work and turn up to all her treatments and be with my wife during the course of her illness. The oncologist came across as extremely snooty, she had very little in terms of personal social skills I mean her words to my wife when she told my wife she was terminally ill you know still ring in my ears; she said to my wife that surgery was no longer an option and radiotherapy was no longer an option and her access to chemo was finite and she wanted to immediately tell my wife how long she had to live which my wife didn't want but there was very little in terms of preparation for her. There was very little empathy on her part to explain to my wife how she was terminally ill.

MB: That must have been difficult?

Kahn: I can't explain how I felt. Then my wife contracted pneumonia and she was in hospital for a few days and the cancer took advantage and spread and the oncologist came in with a whole gaggle of people from the Macmillan nurses and occupational nurses and various other people dealing with palliative care and basically she told my wife the cancer had spread and it wasn't a very sympathetic way she said it at all, and I tried to ask her some questions but she had to go to a meeting at which point I turned around to her and said as far as I was concerned my wife's medical needs that she no longer benefitted my wife in terms of her medical needs and it was at that point I contacted my GP and my GP then agreed to refer us to another hospital and the new oncologist and the whole new team who were absolutely incredible. The difference in treatment that my wife received was in stark contrast to the care and the attention that the second oncologist gave my wife, yeah (p).

MB: And what was different in behaviour with the third oncologist?

Kahn: He took my wife's hand and he held my wife's hand, he used every opportunity to congratulate and praise her right, he was very

sensitive to what my wife wanted to know because my wife didn't want anyone to pity her or giving up on her. I know that my wife would not accept anyone telling her she was going to die, we were going to fight it and he was sensitive to that and I know he was bullshitting. He offered her, the week before she died, he offered her a chemotherapy which had failed the year before and I asked him about it and he said it crosses the brain blood barrier you can still use it and stuff. I know he was bullshitting her but he was bullshitting her for the right reasons and he was giving her hope I just wished my wife was there first.

MB: Why do you think the second oncologist behaved the way she did towards you and your wife?

Kahn: I just felt she was racist and prejudiced against both myself and my wife, me being African and my wife being working class Irish. The oncologist was basically uncaring, she is a white extremely middle class individual, very arrogant and I as an African person being in consults with her I did feel as though I was something that wasn't very clean to be around you know, do you know what I mean? My wife comes from a working class background and her appearance you know she never looked after her appearance and I think that is another factor that influenced the doctor. If me and my wife were white middle class people then perhaps she would have treated us with a degree of more respect. She who just so appalling rude and arrogant towards me and for my wife that I put in a complaint. I think her behaviour might have been different had I been a different colour and we were more middle class you know.

The lengthy extract is used to draw attention to the emotional pain Kahn presented in his narrative and how racism, prejudice and ethnocentrism underpinned Kahn's account regarding the interactions both he and his wife had with the oncologists. Racism against him and prejudice against his wife were claimed in his account. Ethnicity, 'race' and culture constitute a narrative theme to be explored later in section 6.2. However, here these factors were narrated specifically as driving communication difficulties. Social class differences, Kahn's narrative infers, also add to the feeling of being uncared for and not worthy of the oncologist's time. In giving his account, Kahn became both tearful and expressed anger during periods of the interview.

Anger was also an emotion reflected in Ebony's and Sara's narratives. Ebony's narrative presented an account which suggested anger was directed at the clinicians (as presented in the sub-narrative, 'life'bad breaks, (pp.170-173). Sara's anger was directed at being let down by bureaucracy which left her feeling unsupported by palliative care services and this is presented in the sub-narrative: 'Almost there: not quite getting communication right' (p.204). Kahn's story suggested there were times of regret and guilt, particularly about not being aware that it was possible to change his wife's care providers much earlier, rather than a month before she died. In telling his story, Kahn seems to want to make sense of what happened to his wife and the different approaches between the two oncologists.

His narrative presents legitimatisation of his actions in requesting a change of hospitals and commencing a complaints process after the death of his wife. He reflects Hydén's (1997) idea of articulating his wife's suffering through giving it what Hydén (1997) refers to as a strategic value. That is, Kahn's narrative represents his moral grounds to legitimatise complaining about the poor treatment his wife received by the first oncologist. In addition, the narrative reflects a deflection of self-blaming of events which took place for which Kahn is clearly not responsible for. But it is possible the narrative also represents Kahn's actions are to help him grieve by actively doing something on her behalf

6.1.3. Almost there: not quite getting communication right

The research narratives demonstrated how involved some participants were with their care, and how they felt they were listened to by healthcare

professionals providing a different narrative to Kahn's story. I drew on the ideas of Andrews (2002) on what constitutes a counter narrative between the narratives where it is evident the narrators are presenting stark differences in their stories on the same topic.

Ngozi's narrative of interactions with her consultant was in positive contrast to Kahn's experience; however, even Ngozi's narrative suggested that transition of care between different clinical teams (from surgeon to the oncology team), created anxiety.

> **MB**: How did the consultant [the surgeon] make you feel comfortable then, because clearly that was really important to you?
>
> **Ngozi**: He was absolutely fantastic, obviously, it was all happening so fast for me, that I didn't have time to think about everything, but he put my mind so much at rest. I think that's one very important thing when it comes to treatment of anything, it's about meeting your professional and being able to relate and having some confidence in your professional. He didn't make me feel as if our meeting was rushed. He didn't make me feel like, oh, next person needs to come in, to start with. His manner, he exuded calm.
>
> **MB:** Right.
>
> **Ngozi**: I just believe that he projected so much calm, and I just identified, and it was like, yeah, I trust this man. He explained exactly what they were going to do. He didn't just explain the medical bit, what he was obviously going to take out the whole kidney because he didn't think where the cancer was situated they didn't he could go in and cut it out.
>
> **MB**: Okay.
>
> **Ngozi**: He thought it [cancer] was nicely contained within the kidney but it was embedded so he thought a nephrectomy was the answer. He explained to me in a way that I could understand, being non-medical, but he didn't stop there, and he went ahead and reassured me that, okay, some people were born with one kidney and, umm, that he believes that the loss of one kidney will not make my life any less functional than it is at the moment. Because we're looking at the prognosis and they thought the prognosis was wonderful. I think the truthfulness, the sincerity, and just like I said, I trusted him. I don't know whether relational skills are learnt, or they're just an intrinsic part of

people, some people have it and some people don't, I don't know, but he was most calming. He showed interest me as a person. I had told him I was due to start a masters and he said he would try and plan the surgery if possible to have minimum effect on me starting the course. I had the surgery in August so that was great.

Her account presents an active positive engagement with the surgeon. Ngozi's narrative suggested she had pleasant experiences with her clinician, in contrast to Kahn's experience with the first oncologist. Ngozi's account suggested the surgeon's approach gave her confidence, it implied she was being listened to. Her story implied respect for her by the clinician in giving her time during the consultation. She felt reassured and expressed how important it was to have a positive relationship between the doctor and the patient. Ngozi's narrative illustrated what Jennifer referred to in the sub-narrative theme, 'can I ask a question?' (p 193), which is the importance of clinicians spending time with the patient, explaining and re-assessing as far as possible, the patient's understanding of the diagnosis and treatment and providing an environment which encourages patients to ask questions. Ngozi's story contains several references to the other story that might have been told: 'he didn't make me feel as if our meeting was rushed', 'he didn't make me feel like', 'Oh next person needs to come in', 'he didn't just explain the medical bit', 'he didn't stop there', 'some people have it [relational skills] and some people don't'.

Later in Ngozi's interview she tells another story, which would suggest that the accommodating approach by the surgeon might not be the norm. The

changeover from the renal team to the oncology team presented a very

different picture in relation to communication.

> **Ngozi**: After the operation and I went for my outpatient appointment and I saw the surgeon and he gave me the all clear and I was discharged from the hospital. You see, I was a bit confused when I got a phone call from the oncology team, because I thought, and this is my thinking, because they told me the operation went well, I probably wouldn't need radiography or chemotherapy or anything, as long as the kidney was removed, I'll be fine. It hadn't spread and I was going to be followed up in six months and have periodic scans. I didn't understand at the time that I was going to be referred to oncology, so when I got a letter from them I was surprised and worried. The oncology service was not very nice.
>
> **MB**: What wasn't so good about it?
>
> **Ngozi**: It wasn't as nice. Nice is not the word. It was fragmented. Someone called me, explaining to me, asking me whether I would like or I would consent to be part of a survey, no not survey.
>
> **MB**: Do you mean research?
>
> **Ngozi**: Yes, research, and at the time, I thought to myself I would like to, I'd like to contribute anything that I could to help people who might be in my situation or worse. But then I didn't understand how it would all fit in, I was starting uni, I had other appointments but when I got to the clinic it wasn't about the research and I was really confused. The experience didn't stand out.
>
> **MB**: Right. And that was your first contact with oncology?
>
> **Ngozi**: Yes. Umm, a lot of fragmentation. It was, okay, I saw the consultant, and he told me that he wanted me to have a scan, and up to now let's put it this way, up to now, I don't know how periodically I needed to have blood tests, although I know I'm supposed to have a scan every three months, but that's about the only thing I know, and that's because I've asked a lot of questions and every time I've been there I've seen somebody different. They have cancelled appointments and take ages to get another.

The performative element of her narrative changed when Ngozi's narrative

account recounted this experience. Her body language suggested some

frustration with the oncology service; when she shrugged her shoulders and

shook her head. It would suggest from her narrative that hearing the words 'all clear' from the surgeon gave a message of all being well, leading to confusion and heightened anxiety when she was contacted by the oncology team. Organisational processes impacted on effective and clear communication. Her narrative reflects how she wants to get her life back to the 'pre-illness' position ("I didn't understand how it would all fit in, I was starting uni"), reflecting Bury's (2001) contingent narrative type. The lack of continuity and poor communication from the oncology team further heightened her anxieties and Ngozi made several references in her narrative to problems with communication between her and the oncology team. Her account suggests not being informed about the results implied the inadequacy of integration and communication between her and the oncology team.

> **Ngozi**: It was such a change from what I was used to with the surgeon and I'll tell you what else happened, umm, I went in one visit and someone said to me, oh, your CT scan was normal, exactly the same as before.

> **MB**: Right. And what was it before?

> **Ngozi**: I said, what was it before? She said, oh there's a little cyst on your kidney, and I hadn't known that, I didn't know that at all. I said I didn't know that, they said, well, at that point in time, they didn't feel it was probably any cause for concern, but because of your history, they would like me to have an MRI, just to make sure that it's not. It was inoffensive, and that was, to tell the truth, that scared me.

> **MB**: I can understand that.

> **Ngozi**: Okay, I went for the MRI, around two months ago, and no-one's called me to tell me the results. I'm just assuming that because I've not heard anything things are okay, which is really a silly thing to presume, cause maybe I should call.

> **MB**: Will you consider contacting them now?

> **Ngozi**: Yes I guess I should now thinking about, but that consultant oncologist I only saw once and she was probably a lovely person, but she was quite cold and, umm, clinical.

In this part of her narrative, Ngozi implied not surprisingly, a sense of dread at what the MRI result might indicate. The story suggests she may use the lack of communication by the hospital as a basis for believing 'no news is good news'. However, the narrative implied she wanted to know by her comment, 'maybe I should find out' which I considered was inviting a response from me.

Her inaction in not wanting to find out, could indicate some denial, but could also be seen as self-preservation, not wanting to shatter her world of having been successfully treated and must also be seen, importantly, in the immediate narrative context of communicative 'fragmentation'. The unfolding of her narrative illustrates the fragility of coping with the uncertainty a cancer diagnosis brings. Being told about the cyst potentially threatens her world of coping and what Bury (2001) describes her attempts at normalcy.

Ngozi's narrative implies some contradiction in how she views the consultant with the use of words such as 'lovely' but in the same sentence states the oncologist was 'cold', 'clinical', words not used to describe the surgeon. Her account implied hesitancy in wanting to talk to the oncologist, suggesting her relationship with the oncologist was not conducive to encouraging dialogue.

The narratives I have presented illustrate complexities which on one side highlighted quite profound negative narratives on communication, which is then countered as a positive experience of doctor-patient communication. Yet even within the narrative on positive experiences, there exists poor communication, presenting a complex sequel into partially good and partially

bad relations to treatment. Sara's narrative is also reflective on such difficulties with healthcare professionals.

Sara's narrative of similarly ambiguously valued communication, suggests that the lack of cohesion between services placed her in a dilemma. It reflects her frustration at the poor support both she and her father received and indicates this was due to failure in communication and inept bureaucracy.

> **Sara**: When the time came now, dad's pain, he had problems with settling things in his stomach and so on, got in touch with the hospice. They said that oh they just got the referral but they couldn't come out and see him just yet, so I said, well, basically, can someone come and see him, who's got him in the meantime, while we're waiting for this referral who is managing my father, his pain is getting worse. I was just so frustrated, in the end we had to bring him to hospital so that he could get the care that he needed. And that was the bit that really disappointed me. As a matter of fact, I'll go as far as to say I was quite bitter about that part that particular aspect of his care, because I think that they could have really helped with a lot of things. The hospital are really quite good and they were really quite disappointed I had to come to that, because really, with his symptoms, they feel that really he didn't need to come in, but we had no choice. The people that I thought would have been able to help me, the Macmillan, I really didn't feel they were there.
>
> **MB**: That must have been difficult for your family?
>
> **Sara**: I said there's no way he's going to go through that weekend you know he was in a lot of pain. I just couldn't quite know where to stand, the pain the amount of morphine he was getting was helping the pain, but then it's like he was going off.
>
> **MB**: What do you mean?
>
> **Sara**: I could see his eyes were pinpoint pupils so I said I don't really want to give him anymore because I feel I'm overdosing him, and I think where is Macmillan? So I thought, look, I'm going to bring him in (to hospital) because I was thinking I'm going to end up killing my dad having to give him such an increase in opiates, so I thought no, no, I'm bringing him in, I ain't going to kill him with it, you know, so um, at that time I just literally was completed my nurse prescribing course, so I thought, no way, and they (Macmillan) weren't there, you know and I just wondered would it have made a difference.

Sara's narrative account of this aspect of her father's care was very emotional and she was tearful at this part of her story. Her narrative reflected her sense of abandonment by the palliative care team, implying it placed her in a predicament about how to control her father's pain and the emotional turmoil that created. Her account presents pain as a symptom becoming a central issue which re-shaped the illness experience providing what Hydén (1997) expresses as the illness taking on a new meaning, a new reality which presented a change in her world of meaning with her father's illness. Pain gave a different dimension to the illness as narrative in Sara's story. From her narrative there was a suggestion of the immense pressure, responsibility and fear of being left to decide the dosage of opiate analgesia, a frightening prospect for her, even though she is a nurse. Ngozi's and Sara's narratives articulate Hydén's (1997) analysis of the complexities in interactions between healthcare providers, patients and carers can be hindered by structural processes.

6.1.4 Summary

The relationship between patient and doctor has to be built on trust and honesty, which need to be underpinned by effective communication, despite power differences in social positioning in relation to class, ethnicity, race and sometimes gender. The narratives analysed here, illustrate some of the challenges imposed by time constraints in doctor-patient consultation, attitudes of clinicians and the lack of confidence in patients who do not feel able to ask questions or know what to ask. It is clear that time spent in creating an environment for patients to feel at ease and to ask questions, particularly in the case of a life-threatening chronic illness as illustrated by

Ngozi's narrative, pays dividends in the way patients feel about the care they go on to receive and how they respond. In addition, the changing parameters of the illness, as in Sara's story, can create a burdening effect on loved ones when left feeling isolated by healthcare professionals.

The narratives have articulated some challenges with interactions between narrators and healthcare professional and how resistance to poor communication was expressed. Personal value and self-worth were observed in those resistance narratives. Narratives presented attempts at what Bury (1997) refers to as normalisation, which can be negatively affected by interrelations with healthcare professionals. Some narratives reflected Andrews's (2002) analysis of counter-narrative, providing an alternative interpretation to the storyline.

As mentioned earlier in the introduction to this narrative theme, there are multiplicities of factors which interplay in communication, and culture and ethnicity are important features of interactions. These two factors were expressed in narratives and are (re)presented in section 6.3.

6.2 Narratives about Screening

Cancer screening as a health preventative strategy is an important aspect of public health; therefore, availability of awareness of cancer screening services to the public is crucial. In addition, the attitudes of healthcare professionals, in relation to BME patients as well as the gender and gender awareness of health professionals, particularly for gender sensitive cancer screening

procedures for cervical and breast cancer, has an impact on both the usage and re-use of the service.

It is well documented that early diagnosis of cancer improves mortality outcomes and reduces morbidities (Abdullahi and colleagues, 2009; Chinegwundoh and colleagues, 2006; Chui, 2003). The uptake of screening for breast, cervical, prostate and colorectal cancer is much lower in the black community than the white indigenous population. The acceptance of screening processes such as self-examination for breast cancer and self-screening stool collection for gastro-intestinal cancer may not be acceptable to some minority ethnic individuals. Some participants' narratives referred to unawareness of cancer screening services, lack of information, self-responsibility for taking ownership of health and the woman's role within the family as being in the vanguard of the family's health. I framed these sub-narratives within three areas: consequences of poor screening practice; getting access to information; and acceptance of self-examination and self-screening practices.

6.2.1 Consequences of poor cancer screening practice

Cheryl's narrative is reflective of the experiences of three other participants, regarding concerns about healthcare practitioners' skills and practice. She did not have a cancer diagnosis but underwent cervical and breast cancer screening. Her account not only captures some of the participants' accounts (Lorna, Sharon), it also epitomises how poor experiences can prevent further access to screening and therefore compromise opportunities for early diagnosis of cancer in the future.

MB: What have been your experiences of cancer screening?

Cheryl: My experience was fairly positive, especially with cervical screening, umm, but I've had one terrible experience, the last cervical, sorry, the one before last, cervical screening when, umm, the experience had a major impact on me, to the point where I didn't have any screening done for many years.

MB: Are you able to explore that a bit more?

Cheryl: A nurse was doing the testing. She did all the right things, made me comfortable, asked me a few questions, and then proceeded to do the test. But when she put the speculum in she said she couldn't find my cervix. Now I'm a nurse, but as a patient, lying there, someone's telling you you've lost part of your body that you were sure you came in with at the time, umm, was a bit distressing.

MB: I can understand that.

Cheryl: So I laid there thinking where's it gone, what's going on, have I got something awful, which is why she's not finding it, and she tried about three/four times and still couldn't succeed, so I left there not quite knowing what was going on and I never went back.

MB: That does sound distressing. Did she explain why she was having difficulty?

Cheryl: Understanding some of what she was saying at times was difficult, and as a patient, if you can't understand the person who's delivering the care to you, then you often wonder what they are delivering. It is quite a sensitive and embarrassing type of test and she did nothing to reduce my anxieties. This is something that most women are quite scared to have done. It was almost like I was on a conveyor belt and it was quick in, and the fact that she couldn't find it, in the end, meant I guess I overstayed my welcome. She was rushing a bit and all she kept saying, ooh, I can't find it, I can't find it, and well all I was interested in was for her to find it so I could get out.

MB: That experience has affected you having further cervical screening?

Cheryl: After I was so traumatised by that incident, I didn't go back for about six maybe seven years, and then I started heavy bleeding, and I thought, oh my God, here we go now, it's either my age, I'm going through the change or something, you know, I was bleeding intermittently and I got a bit worried and I saw one of the family planning co-ordinators, quite senior one in family planning, and I just said to her, you know, I'm bleeding heavily intermittently and stuff, and she said have you had your cervical test done?

MB: Okay.

> **Cheryl**: I explained to her what happened and I said I don't really want to have it, to be quite honest with you, and she actually made the appointment for me to have it done, there and then, and it was done by a doctor, at that time, in the family planning, and she was absolutely fantastic. If anyone needs it I'd tell them to go to that clinic because she was just terrific, the way she talked to me. She just had such a wonderful personality, so warm, and she took her time, and she still explained everything, she explained how when the results were going to come back that you know what I needed to do, and all this, it was just fantastic, and that experience and she pushed a speculum in, done and out. So while she's talking to me and explaining all this and I'm listening and nodding etc, she was doing her work, you know, I heard her say I'm just going to insert, and the rest was history because it was done, and that to me was a very pleasant experience, and when my next letter come, I'd be running back to her again because she was so good in what she did, so that cheered me up somewhat that day I think. They did find some abnormal cells but I was alright in the end. It wasn't cancer.

This lengthy extract alludes to the difficulties Cheryl faced when she implied being in receipt of poor practice and poor communication by the nurse which heightened her anxieties. Cheryl's narrative suggested poor care negatively impacted on attending any further cervical screening for some years, the consequences of which could have been significant. Using emotive words such as 'traumatised' for an invasive and sensitive procedure, suggested fear and fretfulness, leading to her refusal to have the procedure. There was also fear embedded within her narrative in how she was going to be treated by another smear taker at the time when she was experiencing symptoms which could have been suggestive of cancer.

Other women's narratives did not display such extreme difficulties but how the procedure was managed was more related to the interpersonal relationship between the healthcare professional and the woman; "the nurse really didn't say much... felt impersonal really for such an intimate procedure" (Lorna, talking about cervical screening);" some explanation of what was going to

happen, would have been nice" (Ebony talking about breast screening). Other women spoke positively about their experience of screening similar to Cheryl's last experience: "the nurse spent time with me, gave me time to ask any questions, she was great" (Sara talking about breast screening). Cheryl's narrative reflects elements of being a counter narrative with regards to the earlier part of her story. The dominant storyline is one in which being a service which predominately is delivered by female practitioners, the experience for the woman is portrayed as empathetic. But also in the latter part of her story, "I would be running back", this is counter to how many women would feel about such procedure because of its underlying possibility of diagnosing cancer. However, her story does underline how attitudes and interpersonal skills can play a major role in accepting intimate screening services.

6.2.2 Getting access to information

Accessing information on cancer screening was part of five other participants' narratives, but with differing perspectives. Ebony, Lorna, Jennifer, Sara and Cheryl referred to ineffective targeting, whilst June's narrative alluded to individuals needing to take personal responsibility for finding information.

Cheryl articulates the lack of accessible information about cancer screening and identifies possible community solutions.

> **MB**: Do you think information on screening is easily available?
>
> **Cheryl**: It might be there but I don't think it's visible. You'd have to know where to find it. You've got to know what you're looking for a lot of the time, but there's a lot of stuff out there, but I think it would be difficult for elders, especially ethnic minority elders. The service [NHS] is universal but there's very little targeting of ethnic minorities from what I've seen. I've just recently had my breast screening done, but it was just a letter. Actually there was something in another language attached to it, for a change, but I think the information you got, if you

didn't understand the importance of it, perhaps you wouldn't have gone, yeah? Information I think is vague, maybe it's not to scare you but I had never had breast screening examination and it would have been nice to know what to expect, what was the procedure. When I went for screening, the radiographer didn't explain anything for me. Having your boobs in those positions, and dragging your boobs onto the machine and all this kind of stuff, was scary, you know, you're thinking my God, this is so awful. I said to someone I didn't know my boobs could stretch that far (laughs).

MB: I understand that.

Cheryl: Information could be more accessible for them. I have noticed as a community health practitioner if community support groups are used the information would be more accessible and people could be informed. Like a lot of our Muslim clients, they go to the Mosque, they get information about various things, or they have their little groups that they go into, and they're the ones who give them the kind of information that is required, pertinent to them, because, yes, you can deliver a service, but if there's something out there to fit your ethnic needs, then obviously it's going to be better.

Cheryl's narrative draws attention to recognising cultural and religious differences need to be considered if health-preventative information related to cancer is to be accepted by different minority ethnic groups. However, cultural issues are probably backgrounded within healthcare services for individuals whose language and religious backgrounds are normalised as English and Christian which might lead to healthcare professionals believing there is no difference in what the needs are between African and African-Caribbeans and the host population. In the context of BME issues, 'race' may affect people's experiences with healthcare very differently. This thesis, by focussing specifically on African and African-Caribbean communities, learning from these narratives, provides insights into what interventionist strategies might be helpful in providing these communities with accessible information on cancer.

Sara's narrative also referred to what she believes is a lack of information for the black community about screening and its benefits. She particularly considered being a health professional herself and not seeing information readily available, how difficult it must be for the lay community, particularly the elderly. Sara's story depicted how since her father's illness, such issues have gained centrality in her life.

> **MB**: In terms of targeting information, do you think the information is targeted well to blacks regarding cancer?
>
> **Sara**: I don't think so because I don't see anything. I mean you know I'm in the community and I don't see anything. My Dad had cancer when he was 60 and he died at 70, so for 10 years I've always ever since the first time he had it, my antenna has been up being alert to any information and I found very little.

Imagery, awareness of symptoms of breast and cervical cancer and self-responsibility, were aspects of other narrators' accounts. Jennifer, in her narrative, reflected on the challenges of finding information on screening.

> **MB**: When you think of the black community itself with regards to screening do you think information on screening is accessible?
>
> **Jennifer**: If I was to sort of look at the wider population and thinking of perhaps my immediate group in terms of relatives and friends and that sort of thing which is very mixed, I think those with the professional background will tend to access information and are more aware. I think non professional friends and colleagues may be steered to it if they are pushed in that direction or they are encouraged to but I don't believe generally that they avail themselves perhaps to as much screening information. I think maybe because well if I don't have any symptoms I am going to be okay therefore why look for something if it's not there and oh it's in the hands of the God's so you know when it happens it happens and then I will look at it then, erm, but I think perhaps more public awareness, more advertising that targets particular minority groups and is portrayed by minority groups would send a clear message that it doesn't just happen to other people, that we are part of the other and therefore it is equally applicable to us as a group and therefore it becomes a collective responsibility and a collective initiative that enables us to access services rather than oh it's somebody else's issue.

MB: That's an interesting point.

Jennifer: I am just trying to think back now and see or think of what sort of information was available and if I wasn't in the professional field and I wasn't of an age where I was being screened regularly I doubt very much if I would have been aware of what is available and sort of thinking about the various types of breast cancer in particular and those who are hormonal dependent that tend to affect the younger age group I doubt very much if young black women think about themselves as being at risk particularly.

The narratives above suggested better, more effective targeting of information at the black community. There was also a fatalistic element to her story when she referred to how she perceives others' inaction; "oh it's in the hands of God so you know when it happens it happens and then I will look at it then". With such a belief, looking for information on screening may be considered unimportant as that will not change any outcome. Again, this sense of 'something' which is a higher power than themselves, not having any control of life outcomes, are aspects of illness narratives. Bury's (2001) and Hydén's (1997) frameworks do not explicitly discuss but enables exploration such phenomenon within illness narratives.

Whereas Jennifer's and Cheryl's narrative makes reference to better targeting of information to the black community, June's narrative illustrated her having a proactive approach to her health. This was evident from her asking her GP to arrange for her to attend the family history clinic and her narrative suggests that she believes information is readily available for anyone to access. June presents a different narrative in which her narrative suggests disapproval of individuals who did not take a lead in their care.

June: I think, on the whole, I think for breasts, well I don't know for the other cancers, I think for breasts it's more or less out, the information is there. Perhaps many people have these issues, family-wise, friends, public, celebrities, so I think there's lots of stuff out there and they always advise to at least check a few times of the year, check your own breasts really. The information is out there and if you have an interest in your health, which I think everybody should, whether you're a health professional or not, or you know it is about your body. I think there's enough information out there to at least be to make you proactive for yourself, okay, there's always that scary bit, if it is, you know, that sort of thing, but I don't think that should be a deterrent, and I think it's as much there for any ethnic group really. One thing I noticed about some information leaflets on breast cancer was that it had a photo of a black woman on examining her breasts.

MB: Was that specifically from the hospital that you were referred to?

June: Yeah, that was the information, yeah, there's a photo of a black woman. I only remember because it's this area of London anyway, which has a lot of cultures basically and I suppose they are trying to relate to us. That's a very positive thing. Images are important.

June's narrative account pointed to the onus of responsibility being on the individual, and her narrative suggested she 'blames' them if they are not proactive enough. Her story reflected Bury's (2001) moral narrative through appearing to be self-praising and reflecting her success in living with illness, when she makes the comment, "I insisted on being referred", implying criticism of others who may have failed to be so engaged with their health. It is difficult to know if such a position is related to her being a health professional and therefore placed in a position of advantage to know where and how to access information on screening. Her narrative, however, does share with Jennifer and Cheryl the importance of imagery to make the information relevant to respective communities.

Narratives such as Jennifer's, Sara's and Cheryl's experiences regarding the difficulties of the availability of cancer screening information and services were similar but June's narratives stood in contrast to their narrative accounts. However, all participants' narrative accounts articulated the need for appropriately targeted literature for ethnic minorities. Their narratives articulated wider social contexts regarding screening which are reflective of the everyday talk Hydén (1997) refers to about illness and their narratives draw in the social dimension of illness talk.

6.2.3 Acceptance of self-examination and self-screening practices

As individuals we carry out personal hygiene daily; however, there is something different and perhaps for some uncomfortable about deliberately, purposively feeling and examining oneself, which was articulated in some narratives. Jennifer's narrative account addresses the wider perspective on the challenge of self-examination.

> **MB**: What are your thoughts on doing self-examination?
>
> **Jennifer**: I don't have a problem with checking my breasts. I wouldn't considering my previous work. I mean that was how I was diagnosed and when I felt the lump I actually asked my daughter to feel my breast to see if she could also feel it. But I guess culturally oh yes because you're not supposed to touch yourself or feel yourself, you shouldn't know yourself too much intimately should you from a cultural point of view, erm. So I don't think that people perhaps engage in self-examination a lot, erm, but who should tell them so how do they get to know and that is where I see the big gap in terms of making people aware of what they should be doing and therefore taking charge of their health, but even that is at odds from the cultural perspective if they have been brought up amongst old relatives or a family who have not lived in the UK for very long who see professionals as the owner of information and the gate keeper so therefore well if I need to know something then the doctor will tell me so it's almost, erm, letting other people take that responsibility or seeing that responsibility invested in others rather than them having the control within their hands to do for themselves.

Jennifer's narrative appears to indicate that from a cultural perspective, the acceptance of self-examination can be challenging. There are thus wider socio-cultural dynamics which impact on an individual's decision to feel comfortable about not only the necessity for self-examination, particularly in breast and testicular cancer, but conducting such examination. Cultural taboo in self-examination is part of her perception of the resistance to examining the body. Jennifer's narrative suggests that such reticence might provide some explanation as to the higher mortality rate due to late diagnosis of breast cancer in black women. Her narrative also referred to older people who have a reliance on their general practitioner advising them of any health concerns and therefore they do not see the need for any action on their own part. Once more, Jennifer's account reflects Bury's (2001) moral narrative when she describes black elders' behaviour in terms of seeing professionals as 'the keeper of knowledge' and therefore exonerates them (the individual) from blame if they do not undertake preventative measures. By having such a belief, removes any 'blame' on their part for inaction and any subsequent development of cancer, preserving their self-worth. However, there is also a consideration regarding life events, pressures of living, may overshadow the 'will' to seek out advice and information of self-examination.

Sara's narrative again suggested that even when the older person is advised about a particular screening service, it might not be acceptable to them, but also that for male elders especially, doctors are not gatekeeper experts so

much as figures to avoid, with women family members acting in a classic health gatekeeper role.

> **Sara**: He [her father] can be a bit of a minx to tell you the honest truth and it will always be in the back of my mind that that is one of the reasons why it progressed on and we couldn't control it, his cancer, because for two years Dad has been suffering from bleeding down below. Now I've always told him that he should go to the doctors but he said I don't go doctor. My mum was sent a package about stool collection, to detect cancer, and she had to sort of send off some stool or something. She was okay. Dad was sent that package, but there was a little bit of ignorance and some pride involved, there's no way that he is going to do that. I said I'll help him but you know he said there's no way I'm going to do that. What they send me that for, you know, and so on, you know, and I just think I'm laughing now and I think oh God, just typical Dad, I mean but on a serious note, you know, we should really have done something because maybe they would have picked up something then. But there's no way I was going to get Dad to do that. I don't know how I would be able to bring it across to him that it's really important (laughs). Even though I tried to explain to him you know the benefit of doing it, and he turned round and said, well, I'm not going to do that.
>
> **MB**: And I suppose particularly for male elders, visiting GP's is not common*.*
>
> **Sara**: It's true. They didn't, and it's the same, not just my Dad, my uncles, everybody, none of them go to the doctors. I was telling my brother to have checkups, I mean I told him we don't know if what dad had was genetic so get checked. They don't go to the Wellman Clinic, nothing at all, basically what they tend to do, if they're not feeling well, or they want something they pick up the phone and they call me and then I have to tell them, look, you better go and I'll take you or such and such.

Undertaking the collection of the faecal sample, Sara's narrative suggested was abhorrent to her father and she compares his behaviour to her mother suggesting a difference in health behaviour between men and women in her family. Her narrative also typified the role women play in taking the lead in family health and her account articulates the lack of engagement by the men in her family in taking responsibility for their own health. Sara's narrative

suggests regret at not being more forceful with her father and conveys some

self-blame in not insisting her father undertook the bowel screening test.

Carers 'narrative on illness is not addressed in Bury's (2001) and Hydén's

(1997) typologies, but were important narratives to learn about inter-

relationships and the impact of the illness of loved ones. The issue of self-

blaming by carers was also illustrative in Kahn's narrative.

> **Kahn:** I didn't know anything about asking for another doctor's opinion. I was just so mad at the way the first oncologict treated by wife, I went back to the GP and told him how if felt and he just said 'I will talk to the oncologist' Next thing she was referred to other doctor. I just wish I knew earlier, (p) maybe she would have survived longer (cries).

Kahn's narrative was very powerful in how it presented the pain of self-blame,

from his perspective not being more forthright as the husband, protector,

advocate for his wife. Unpicking these feelings within illness narratives for

carers illustrated a particular sensitive impact of illness on significant others

which is not easily surfaced in day to day discourse but emotionally is draining

and not an area explicitly explored in Hydén's (1997) and Bury's (2001) illness

types.

6.2.4 Summary

Screening is a significant cornerstone in cancer care services; its access can

have an effect on life and survivorship. Participants' narratives, apart from

June's, suggest there is some difficulty with readily available, understandable,

targeted information on screening for minority ethnic communities. Self-

responsibility for healthcare was a major issue for June and that accountability

for health rests with active engagement from the individual. However, this

'expert patient' discourse from June needs to be considered within the wider contexts of other factors such as class, level of education and the status of BMEs which can provide an alternative perspective on self responsibility, which Jennifer's and Sara's narratives presented.

Screening procedures have to be acceptable to the community if they are to be used and culturally there are challenges with undertaking practices such as faecal collection, clearly demonstrated by Sara and cultural constraints related to breast self-examination by Jennifer and Sharon. Although there was no mention of religious dogma implied in their narratives, this cannot be ignored for the wider black community.

The men in the study did not discuss screening in their narratives. The widowers spoke of their former wives being more focused on health within the family and who took the lead for them, reinforcing the gendering of health gate keeping. There is no national screening policy for prostate cancer and Michael presented to his general practitioner with symptoms of the disease. In his narrative account he articulated that more awareness should be made about prostate cancer in the black community, linking with other participants whose narratives have also given accounts of lack of specifically targeted information for the black community. Added to this issue of information provision is the possibility that some level of complacency by healthcare professionals could exist because the majority of African and African-Caribbean Londoners speak English, and some of them share the same religious following; therefore it is possible that their specific needs as these narratives have alluded to are not addressed because they are not seen as

requiring anything different. The narratives in this subsection reflected in particular Bury's (2001) moral narrative especially in relation to self-worth, exoneration of inactions, but areas which neither Bury's (2001) or Hydén's (1997) frameworks explicitly addressed (carers and self-blame narratives, self examination) were particular areas of importance to capture.

6.3 Culture, ethnicity, race and cancer

Within each narrative these concepts were present. For seven participants their narratives did not reflect that culture, ethnicity and race had a negative effect on relationships between themselves and their healthcare team. In five participants narratives, race, ethnicity and culture were presented as major issues between themselves and their healthcare practitioner. These differing perspectives led to sub narratives, which I have entitled: Seeing me for who I am, Accepting who I am, talking about cancer in the Black community.

6.3.1 Seeing me for who I am

Healthcare professionals taking the time to recognise and address the cultural needs of participants, was an important part of narratives of participants feeling respected. Ebony's narrative is reflective of other participants' narratives in which ethnicity and culture were factors linked to a lack of respect by healthcare professionals.

> **MB**: During your treatment do you think there was any consideration given to meeting your cultural needs?
>
> **Ebony:** No, erm, not really. When I was being told about chemotherapy and the nurse mentioned something about scalp cooling cap. This is meant to cool your head and reduce your hair loss.

MB: Yes I am familiar with that.

Ebony: I asked the nurse if I needed to prepare my hair being a black woman. Did I need to do anything? She said I needed to wait until when Monica was on duty. I guessed before I saw her that Monica was a black nurse.

MB: Was she able to help?

Ebony: Yes but was it right that I should have to wait for a black nurse? Why wasn't there any information about this? When I asked about prosthetic breasts I was given white prosthesis, which I felt were unsuitable and quite frankly an insult. I thought what I do with these? How insensitive. I asked about breast prosthesis for black women, I was told there weren't any. I know now things are better now but for me at the time there were no options.

MB: Could you tell me how you dealt with that?

Ebony: Well there was nothing they had, so I decided to go without.

MB: How did you feel about that?

Ebony: It was, erm, very difficult initially. But I actually felt more comfortable. I felt this is who I am and I don't know what gave me the strength to feel that I was not going to be concerned about what people might think about me.

MB: Could you explain that a little more?

Ebony: I don't know really. I went to a retreat some months after my last mastectomy and really felt at peace with myself and comfortable with who I am. And then the charity for black women, gave me strength and inspiration.

Ebony's narrative suggested a lack of support in relation to services (no appropriate breast prosthesis), the lack of information or understanding about what she needed to consider in relation to the effects of hair loss, implied indifference in meeting her needs. The account suggests the nurse's actions were inappropriate, insensitive and implicitly disrespectful. Her narrative of reliance on a black nurse to advise on hair care points towards a presumption that because they are both black women there would be a tacit understanding

of what Ebony required. This had undertones of being ignorant of the cultural differences there are within, as well as between communities. Ebony does not mention whether the nurse was African or African-Caribbean but simply that she was black. Ebony, however, is of mixed parentage and unless the nurses' ethnicity was similar, it could not be assumed that both women share the same cultural background.

Ebony's narrative implies an act of bravery and defiance in choosing not to accept white prosthetic breasts. This is understandable, as they would not enable the recapturing of her identity as a black woman. From the suffering (of a double mastectomy), her story presents Hydén's (1997) reconstruction of self through the re-emergence of a new identity. The account articulates a sense of self-discovery and active engagement with her illness. Her approach to coping with the effects of the illness and treatment expressed in what she says in her narrative links the ordinary and moral components of her story.

Ebony's story also indicates the social context of illness through having links with a charity in which breast cancer becomes a public storyline. Within the confines of support group illness for all the women has a shared understanding of the personal and social consequences of the breast cancer. Ebony's story implies she established a means of incorporating her illness into an altered lifestyle to reclaim a 'normal' life, which is re-designated containing the illness. Furthermore her narratives indicate what Bury (1997) refers to as legitimatising her actions to regain control of her life and continue the journey of self-discovery from her new identity.

Sara's narrative presents a cultural perspective which highlights the cultural heterogeneity between African and African-Caribbean communities, when she spoke about the care her father received in hospital.

> **MB**: In terms of the experiences that you had, did you think that cultural issues were met and understood by health professionals?
>
> **Sara**: I think, to some degree. It depends on the health professional but I was always having to be an advocate for him. When he was in hospital, I have to say, no, which surprised me in a way because the people that I expected that would go some way to understand, didn't, because the Caucasians understood more than the Africans and there quite a lot of African nurses and I don't think that they fully understand certain things, yet there was one Caucasian nurse, you know, when Dad's you know saying 'oh, get away from me', ' don't want none of that', you know, so she said, 'oh, I understand, these Irish and these West Indian, they're so much alike, oh don't worry, I don't take anything personal', but I did have a little problem with some of the African nurses which I'm sad to say, and one thing as well, umm, when Dad was in a lot of pain, he wouldn't really say anything, he was quite stoical, but you could tell by his facial expression and so on and this other nurse, she, when she's on (the Caucasian nurse), he's fine, but when she's not there, I was worried so I think there's something that she understands, more. The pain, umm, I found out always I got to be an advocate for daddy, but, umm, I think they could have been you know, people could actually look on him and see that he was in pain, but you know. I don't know whether it's because she's that kind of nurse, but it's just the mere fact that she's Caucasian and she understands and they're black and don't seem to understand. So in a way it's not quite as I expected.

Sara's narrative suggested how she was troubled by the lack of attention and insight shown regarding the care her Jamaican father received from some African nurses. Her narrative implies the approach and attitude of the white Irish nurse was more positive and responsive, which surprised her. Sara's account seems to suggest she made the assumption that as black nurses they would understand his needs and it was a shock to her that did not happen. Whether the differences in behaviour between the African and Irish

nurses were to do with lack of empathy, lack of understanding or culture, it is difficult to judge from her narrative.

Although African and African-Caribbean cultures have similarities in their roots, there are cultural differences between and within African countries as there is in the Caribbean islands. Sara's implied assumption is that as black nurses they should have been perceptive in recognising the needs of her father; however, if the African nurses were trained in their country of origin and migrated as adult professionals, it is unknown as to what their training entailed, which could impact on their attitudes and beliefs and behaviour. Sara's experience is a reverse of the situation, Ebony presented, (subsection 6.3.1, pp.225-226) in which the Caucasian nurses expected a black nurse to be able to advise on a basic aspect of care. Sara's narrative involved expectation that black nurses would be able to interpret her father's cues and would 'know' what should be done for him. Sara's narrative also makes a link between culture, equality and respect, when she indicates that treating all people the same is implicitly unequal, especially when a patient's culture is not considered. This narrative led to the emergence, here and in other similar narratives of what I call, 'culture, the elephant in the consulting room'.

> **Sara**: Well my view is that cancer, everybody is grouped in the same category and that's it, never mind whether you're Polish, black and so on, you've got cancer; if you've got cancer of the colon, this is what happens to you regardless, never mind what your culture needs are, your cultural beliefs and so on. I found that from my angle there was a lot to be done by doctors and nurses.
>
> **MB**: How did you find health professionals approach was towards you?
>
> **Sara**: Generally I didn't have problems, but actually it makes me wonder because dad's had a partner, obviously she's from the West Indies as well, and, umm, I found it quite interesting that when she liaised with people, she couldn't get as much as you know support, and

then she finds she has to pick up the phone to me; and then I have to go and I really hate doing this, because I'd rather be anonymous, but I find I have to say I am a nurse and I this, and I that, and so on, and then suddenly it's okay, right, and suddenly they speak to you in a different kind of way, which really annoyed me because I saw the partner, she is the number one, and she if she come and say I need this, they should be able to give support. My impression is that they don't respect her position. Well, I just feel that they just didn't respect her and maybe there was something about education and not thinking she was well educated.

Sara's account suggests the need to be a 'broker' between healthcare professionals and her father's partner. Her narrative indicates the need to use her 'power' of being educated and having professional authority to intervene, a role that she implies in her narrative she was reluctant to take on. This is representative of what Hydén (1997) refers to as a strategic focus to her narrative as it illustrates how she utilises her position with other health professionals to intervene and make representations, albeit reluctantly, on behalf of her father and his partner. The reluctance in her story refers to the respect she has for her father's partner's position and not wanting to be seen as replacing her or taking over her role. Her narrative further expands on the challenges faced by the partner with clinicians.

> **Sara**: What I found really interesting actually, because she's got a good friend, Gloria, who's white, and when Gloria was with her, yeah, that's really strange, because when Gloria was with her, they (the doctors) were like speaking more to Gloria. Which I don't know why they would do that. I just found it very strange.
>
> **MB**: That is interesting.
>
> **Sara**:I mean Gloria is a good friend of Dad as well and you know Gloria will speak up and so on, but still, nevertheless, the way I see it is that if you come to me, and you say that you're someone's wife, and then you've got a white friend there, I'm still looking at you. I suppose it could have been avoided because she accompanied my Dad's partner, because I couldn't and that was the time when he was told that it's

gone to the liver (the cancer). And I just wish I was there. I didn't think that they would have said that, I really didn't, because I've been going to all the appointments. My dad's partner said that although it was great that Gloria came, she wouldn't want her to come with her anymore. And I think its because she felt undermined which is a shame because then that put pressure on me to make sure that I'm available and if I'm not what would she get out of any meeting with the doctor. That did sit on my mind quite a while.

Sara's story suggests regret at not being able to attend the consultation to support her father when he was being given a poor prognosis. Her narrative implies clinicians disregarded her father's partner, referring questions and answers to her Caucasian friend; and Sara associates such actions as having a cultural connotation, being disrespectful, undermining and ignoring the partner. From the lack of engagement by the oncologist with the partner, Sara's narrative suggests the partner felt ignored and therefore disempowered to ask questions or seek clarification.

Sara's narrative very explicitly represents the impact of cultural and socio-economic status and suggested that judgemental attitudes of healthcare professionals compound the illness experience for the individual and their family. Hydén (1997) refers to the role culture plays in the illness narrative, but behind these stories, was also the impact of ethnicity, which is not so explicitly addressed in the typologies of Bury (2001) and Hydén, (1997) but provides a framework in which ethnicity can be overtly presented within the interpretation of the narrative. The experience of being 'invisible' when with Caucasian friends, at a consultation was also part of Kahn's narrative.

> **Kahn**: When I complained about the oncologist I went to see the head of cancer services at the hospital that was supposed to investigate my complaint. I had my Jewish friend with me who is white and my wife's

brother (White Irish). As I was going through the complaint with the doctor, he never once looked at me or answered me, but he acknowledged my friend and he spoke to him and my wife's brother, but he never once looked at me. I don't know.

Kahn's narrative has implied connotations around ethnicity and racialised practices by the doctor towards Kahn. His comment, "I don't know" refers do an exasperation at the doctor's attitude and Kahn's sense of nothing will change since he saw the doctor sharing the same condescending attitude as the doctor he was complaining about. The doctor's behaviour apart from being racialised was to exert his power thereby controlling the situation and interaction.

As with Sara, Cheryl's narrative reflects on how culture must be considered in healthcare and Cheryl relates this more widely to NHS practice.

> **Cheryl:** On a National Health Service level, I'm not saying you separate black people from white people or whatever, but I think one of the things that we should be doing, if someone's doing cancer care, they need to be aware of the cultural needs of their clients or the population; because it can make the difference to someone dying with dignity if they're going to die, or really going through their treatment feeling that people respect them, they respect your culture, and so on and so forth, and I don't think people know enough about different ethnic groups in order to promote that or deliver it. You really need people to fully understand and appreciate the differences that we have and value those differences because, just because I'm in England, doesn't mean everything an English person does is right. There's things that we can take from other cultures in order to make the care that we deliver, or the service we deliver, more appropriate to suit their needs. So being more respectful of people's culture and maintaining their dignity that's a fantastic step forward.

The holistic individualised care called for in Cheryl's narrative cannot be achieved if cultural understanding of the patient is ignored and she suggests

culture should be embedded in clinical practice. Her account thus articulates the wider societal issues of health policy and service delivery that impact on the illness experience for the individual, forming the kind of account referred to by Bury (2001) as contingent narrative.

6.3.2 Accepting me

Sharon, Ngozi and Mary articulated in their narratives positive experiences of health professionals taking account of their culture and ethnicity when discussing care and treatment, suggesting their culture and race were not ignored by healthcare professionals.

Sharon's narrative adds a different dimension to the interrelation between culture, race, ethnicity and cancer care. Sharon arrived in the UK six years ago, making her the most recent arrival in Britain in comparison to the other narrators. Her narrative suggests she had some difficulty reconciling her immigration status with the right to free healthcare.

> **MB**: What are your feelings about how you have been treated by the doctors and nurses?
>
> **Sharon**: I felt no prejudice at all from being black, you know I wasn't born here so not being born here and being an immigrant even though I have paid my dues, I pay taxes you know, I am entitled to the services as everyone else but parts of you feel that maybe you I know it is a silly feeling really but you kind of feel that you are probably using the resources of people who should be getting it.
>
> **MB:** That's an interesting view. What makes you feel that way?
>
> **Sharon**: I guess maybe it's because I wasn't born here and although like I said I have paid taxes never claimed anything, I have at times felt a little guilty. But I have never felt prejudiced in any way by the doctors and nurses... When I was referred to the specialist hospital I was given top-notch treatment. They spared no expense really in terms of the all the tests and scans they have given me you know, erm, the professor referred my case to people in Europe and America you know. I mean I am a black person with cancer but I have never seen myself as a black

person with cancer you know so maybe that is the way I just think. Coming here and coming out of being a majority (referring to black people being the majority in Trinidad) to being a minority, I do see colour as being an issue here but personally (p), I don't know I just feel more grateful.

MB: When you say grateful, grateful about what?

Sharon: That is probably the wrong word. I am grateful for the kind of care you get and you grateful that people treat you as a person and not as a colour you know, erm, and that has been my experience and I know for many people it would be different; if people have had prejudices then I didn't feel it. I have always felt respected really in the whole scheme of treatment and in terms of the medical side of things I have always felt that you know I was treated with a high degree of respect. They were interested in me as a person.

Sharon's narrative presents a complex picture of her grappling with her inner beliefs about herself and what she feels are the rights and wrongs of receiving UK health services. Her account implies being an outsider, maybe not feeling full acceptance by the wider indigenous population, even though from her narrative, she did not experience prejudice, she recognises that it might be an experience others have.

Several times throughout her narrative, she made reference to 'paying her dues' and this suggests a socio-political context possibly referring to how some parts of the media and society portray immigrants in a negative light, associating immigrants with receiving benefits, being lazy or if they are working, being seen to be taking away jobs from the host community. She presents a positive counter-narrative to what is considered a dominant negative narrative about migrants. Sharon's narrative declares she is not the negative figure mainstream media portrayed. Her narrative also represents an intersection between migration, citizenship and illness, in which ethnicity is also a factor. This could possibly represent a double narrative, that is, being

aware of the allocation of resources and therefore lucky to be in the UK at the time of diagnosis, but also a story telling her contribution to society, which sits against the backdrop of negative images portaged by some in the media and therefore feels she has to prove having the right to access and receive health services.

A comparative realistic assessment of her situation is also another side to Sharon's narrative when she uses the word 'grateful' which seems to reflect not only on being treated well, but also refers to comparing healthcare between England and Trinidad. Healthcare is not free in Trinidad and Sharon recognises that having a cancer diagnosis and accessing treatment in Trinidad would have been challenging; and the outcome for her may not have been so positive. Her narrative suggests she considers her good fortune at being in the UK when she was diagnosed with T-Cell Lymphoma and therefore feeling 'grateful' was deeply meaningful, not a response related perhaps partly to her own feelings of disentitlement, but also an assessment of the relative health resources available in her home middle-income country and a host, high-income country.

Sharon's story presents a paradoxical situation. She talks positively about issues related to race, ethnicity and culture, related to her care, but also presents underlying wider societal issues in relation to those concepts and reflects on her cautiousness in being receipt of care. In her narrative she stresses having been in continuous employment since arriving in the UK, paying tax; and yet she presents a narrative which suggests guilt at accessing

health services, using treatment and having occupied a hospital bed that somehow she is less deserving than an English person. Her account presents an implied lack of total acceptance in the UK by the indigenous population.

 Through her narrative she conveys aspects of herself that add additional pressures to having and accepting a life-threatening illness; her narrative suggests these factors add to Hydén's (1997) reference of the narrative construction of an illness world and acknowledges Bury's (2001) contingent narrative in how different components of life events become related to and hence form the illness narrative. Sharon's narrative suggests how external dimensions add to the framing of her illness narrative. Some narrators' narratives illustrated an internal conflict and indecision with reference to ethnicity and race being factors which played any role in the care they received. This was significant in wanting to be accepted and acknowledged by healthcare professionals.

Ngozi's narrative suggested she had difficulty in reconciling culture, race and ethnicity in relation to her experience of cancer services.

> **MB***:* Do you think there were any cultural issues as to why things weren't being done as well as you feel they should be with the oncology team?
>
> **Ngozi**: That's interesting I (p) would choose not to think so.
>
> **MB**: Can you explain that a little further for me?
>
> **Ngozi:** I would choose not to think there were. I think if you ask that question how I can say, (p) I would probably believe, right, it might be, there's a possibility that I get treated different or I'm not given as much as I would expect, if I was probably upper middle class. I believe that there would be a difference in the way I was treated on that basis, more than race.

MB: Okay. So in terms of level of interaction, you think the difference in how you were treated was based more on how they see you in terms of your class status?

Ngozi: I kind of believe so. I'm not absolutely convinced.

Ngozi's account seems to suggest she struggled with this issue; she implies that race or ethnicity could not or would not affect care being delivered, yet she also exhibits doubts about her own answer and beliefs. She took some time to answer the question, pausing several times and it was interesting that she seems not entirely convinced by her own answer. Her narrative suggests social class as more relevant than race, to poor delivery or access to services. Positioning ethnicity or 'race' as relevant was clearly an unpleasant possibility, but she does seem to register 'race' is not completely outside the equation of playing some role in the care pathway. In part, Ngozi reflects, I believe, a counter-narrative on the issue of 'race'. Here, Ngozi's narrative contrasts with Kahn's narrative in the sub-narrative "acknowledging me': I do have feelings" (pp. 200-203) and also through her comment "I would choose not to think so", partially representing Andrews (2002) notion of a counter-narrative.

6.3.3 Talking about cancer in the black community

Narratives from six participants widen the focus beyond the participants to the black community, discussing how participants perceive that talk of cancer can raise concerns within that community. There were many similarities between the narrators' narratives about how African and African-Caribbean communities addressed cancer, but a striking difference appeared in Ngozi's narrative. She spoke strongly about cancer being 'hidden', not discussed, within the Nigerian community.

Ngozi: Community thrives on secrecy, shrouded in hush hush, it's nearly as if you say it might consume you. It's superstition around, like a jinx, once you start, once you say it, you might be exposed to getting it. This is nonsense, but real. My Mum, up until today, no-one knows that she had cancer, but for me, I don't really believe in the secrecy. I don't believe in broadcasting but if it's there, it's there, you can't deny it. And there's this whole thing about being strong and having faith. You know, this is really interesting that we're talking about this.

Ngozi's narrative account makes reference to her family and seems to suggest her mother's behaviour is reflective of what she perceives as the wider Nigerian community in shrouding cancer under the umbrella of secrecy. There is some implication from her narrative that she collaborates with her mother in the silence but later in her story justifies her actions, suggesting it was necessary not to divulge any knowledge of her mother's cancer in order to preserve her mother's emotional wellbeing and mental health and to obviate concerns about being ostracised from the community. Ngozi's narrative reflects Bury's (20021) contingent narrative by using silence as a strategy to normalise her situation, disguising the illness in order to present to others outside the family her mother's pre-illness identity.

Mary's account of cancer, when referring to the Ghanaian community, suggested there was more openness in that community about cancer but suggests too that death is inevitability associated with cancer. Her narrative suggests secrecy is not an issue but there is, nevertheless, she points out, an irrational fear of the word 'cancer'.

Mary: They don't talk about it, most of them, the name cancer; if they say a family has got a cancer it is a thing the whole family will be like she is going to die; back home they think there is no cure you see and

no medicine so it is like you know, I don't know how to explain it, they are scared of the word cancer, when they hear the name cancer they don't hear it well, the last minute before they heard it so it is like everybody they feel so sad and bad and why, why, why.

MB: Is that related to a sense of hopelessness?

Mary: Yes there is no hope. There are very little facilities (in Ghana) and resources there and because of that there is this strong belief that nothing can happen and therefore there is no cure for it at all.

From her narrative there is a suggestion of despair, sadness and frustration when she repeatedly states 'why'. "Why don't they talk about cancer? Why isn't there better treatment?" Referring to lack of treatment in Ghana seems to encapsulate her anguish. Her comment, "they don't hear it well, the last minute before they heard" refers to late diagnosis; in this situation, death is highly likely and this perpetuates a sense of hopelessness. Her narrative links with Bury's (2001) idea of contingent narrative in the way that it depicts how different components of an illness are presented (that is, in this case, frequent late diagnosis of cancer leads to high mortality which creates the belief in the community that cancer is incurable). Later in her narrative she does, however, suggest that there is a difference in believing in cancer survivorship for Ghanaians in Ghana and Ghanaians living in the UK.

MB: Within the community if you are an individual that has been diagnosed with cancer how does the community treat you?

Mary: This is like a family thing, they will treat you like their own family, they will welcome you and some of them will be, the fear will grip them and oh they don't talk like. Nobody is happy, there is no happiness, they just come and sit down and it is like mourning.

MB: Do you think attitudes are different for Ghanaians who are here in the UK? Do you think they see cancer differently or is there that same kind of underlying fear of no hope?

> **Mary**: Here because of the facilities that we have here they are not scared so much or they don't talk about it so badly, it is only the other side (in Ghana) but those who are here talk about it like oh it is okay and then the doctors will try you know that is how they feel about it.

Migration and potential altered attitudes to cancer are bound up in Mary's narrative; however, the histories of such beliefs are inertial and hard to change. They may hang over migrants in the UK and pass also to younger people of Ghanaian origin. Cultural influences on illness narratives are portrayed in the typologies of Bury (2001) and Hydén (1997) but with increased multiculturality of the UK, the impact of migration can be an important aspect within illness narrative, which has not been articulated explicitly is either typologies. However, their framework allows for its inclusion and links with ethnicity.

Lorna, Cheryl, Sara and Joseph are all Jamaicans; their narratives also suggest there was also an increasing openness to talking about cancer in the Jamaican community, but there was some ambivalence regarding treatment and its success. Michael, also Jamaican, contrasts with their views on openness. Unlike the other four Jamaican participants, Michael's narrative suggests his view is quite scornful about those who choose not to talk about cancer.

> **Michael**: Me a tell you [I am telling you] I don't understand this foolishness of not wanting to not talk about it. If you nah [don't] talk about it, how are people phee [to] know what to do? Talking helps people to learn. I told everybody. I never made any secret of my cancer. I memba [remember] a couple of years ago hearing about a friend of mine who had cancer and the first I knew was at his funeral.
>
> **MB**: Why do you think people don't talk about it?

> **Michael**: I really don't know, maybe ignorance or scared they will have cancer if they just say the word.

Here, Michael hypothesises about beliefs that recall those Ngozi describes in Nigerian communities. The fear saying the word 'cancer has malevolent connotations, and hearing stories, from those who do not themselves share such a belief in this supernatural power of the consequences of saying the word cancer is important because as people they live among those who do. Such beliefs can provide a basis for understanding the problems with accessing services, of the challenges with delivery cancer preventative measures.

The power of the word 'cancer' can as these narratives illustrate be a significant factor in the story, because it is discussed within a cultural framework which can be hard to break, even with the availability of free access to cancer screening and cancer treatment. These narratives also present a different perspective on illness narratives which are not explored in Bury (2001) and Hydén's (1997) frameworks, but through adaptation for this thesis, expanded to address illness narratives for African and African-Caribbean communities.

In Joseph's narrative, although he believes there is more openness than before, he also refers to difficulties some friends had saying the word 'cancer'.

> **Joseph**: Well funny you know there were some people who did have trouble speaking about it. They would not actually say cancer but would say things like big 'C' or just say Rose had 'that disease' but that didn't bother Rosie.
>
> **MB**: Did you and Rosie talk about her situation?

Joseph: Oh yes. She was extremely strong. She was very brave. She wanted to make sure the wills were in order, she had planned what arrangements she wanted for the funeral. She wanted to talk to her daughters but they found it very difficult to talk about her situation. It was a comfort for her when Charmaine visited as she could really talk about how she felt with her.

MB: Who was Charmaine?

Joseph: She is my daughter-in-law. Rosie was especially house-proud and the kitchen was an important space to her which she treasured and it upset her to know that people who she would not normally have in the kitchen were in and out of there. People were coming wanting to pass on their best wishes but when Rosie was well there was no way those people would be allowed in her treasured, precious kitchen. But she could not really move from the bedroom as she was needing oxygen so she felt she was losing control of what was happening at home and I didn't realise how this was upsetting her until Charmaine told us. When Charmaine told me I put a stop to that. I know Charmaine sometimes felt worried about how Rosie's daughters would feel about her and feeling that she was taking their place but actually they were grateful and I know they let Charmaine know that. They were very close.

Joseph's narrative reveals how social support can be intrusive and can create the loss of functionality the biographic disruption Bury (1991) refers to, leading to dependency on others, which appears to have been a source of frustration for Rosie. His story reflected the important matriarchal basis of the family structure and how the illness disrupted Rosie's ability to take control of what was happening in her home. Joseph's narrative suggested he saw his daughter-in-law as an important conduit for himself and his step-daughters, reflecting the significance of family support. Clearly the daughter-in-law was a central anchor for the family in the latter stages of Rosie's illness and Charmaine's role within Joseph's story demonstrated how it helped him to cope with the loss of Rosie. His narrative illustrated how he drew strength

from his wife's tenacity and presented an inner strength and a deep belief in not being afraid of death.

Some narratives expressed fears in the community of saying the word cancer, but the narrators themselves do not subscribe to such views: their narratives are about strength and bravery in coming to terms with the terminal illness or the loss of a loved one.

6.3.4 Summary

The study narratives presented a window into the complexities surrounding 'race', ethnicity culture and how respect and dignity were bound up in the narratives. Fear of the word cancer appears across both the African and African-Caribbean narratives. The narratives showed that when healthcare professionals considered culture and ethnicity as part of their care, individuals were receptive and trusted clinicians to make decisions which were right for that participant. Narratives, which implied indifference or lack of cultural sensitivity by healthcare professionals also suggested that these features created additional difficulties in coping and living with cancer.

6.4 Conclusion to all five narrative themes

The three narrative themes explored in this chapter (culture, ethnicity, 'race', 'screening' and healthcare professional-patient communication), offer answers to how culture, ethnicity and societal constructs influence cancer experiences, how those constructs influence the stories narrators told and the way they told them and what were the good and bad practices which affected narrators'

experiences. The complexity of ethnicity and its associated links with racism and prejudice are borne out in the narratives.

Narratives articulated challenges not only in what was said, but in how people were spoken to, in cultural differences in interpretation of information and in efforts made by healthcare professionals to clarify, explain and give time for discussion. The intensity of emotion about racism and prejudice was different between the narrators but was clearly a feature of cancer experiences for some narrators. In other narratives, indifference or lack of consideration of ethnicity, rather than racism seemed to be part of other narratives. Still other narratives in which narrators did not express any concerns regarding racism, nevertheless indicated that on a wider scale prejudice and racism still exists in healthcare and therefore by default in cancer services. Cultural heterogeneity between African and African-Caribbean communities was a finding I was expecting but it sometimes appeared in unexpected ways (Sara, pp.227-229). This heterogeneity has not been explored in any detail in previous research, but is significant for how healthcare messages are received and is discussed further in Chapter Seven.

Other themes in the narratives related to ethnicity and culture, which articulated how experiences of healthcare in their home country shaped for some narrators their view and expectation of healthcare. Furthermore, culture, as well as education, appeared to impact on interpreting information. Interpersonal communication between the narrators and healthcare professionals was evidently affected by ethnicity and societal influences. Also for some narrators, their health professional role placed them in conflicting

positions of understanding healthcare organisational structures and systems and needing to have their own informational needs met. The position doctors held in some narrator's eyes impacted on their dialogue in consultation.

Although this has been in general terms in other research, specific differences in culture between the clinician and patient played a strong part here in the positive or negative communication experiences. Investing time in consultations was important in relation to communication. This has been observed in previous studies in regards to lack of engagement but what was also identified in the narratives in this study particularly when narratives discussed the wider community was how deference to the position of the clinician negatively affected communication, particularly for black elders.

My sharing cultural norms with some of the Caribbean narrators (Ebony, Sharon, Joseph, Michael) meant there were some paralinguistic features of the dialogue, the power of which cannot be truly captured in text, but which helped me to frame the emphasis of what was being said. These culturally specific paralinguistic features of Caribbean English were in some narratives a distinct feature of how the story was told. The 'sucking of teeth' would illustrate that point being was either funny or frustrating. Thus the 'sucking of the teeth' has two opposing meanings, which are determined by the context of the point narrators knew I would understand its contextual use.

Narratives also gave some insight into the need for closer examination and understanding of culturally shaped intransigence about self-examination, an issue also referred to in Chapter Five. For some participants there was a redefining of the 'self', which emerged through the chaos of the illness. The

strength and tenacity of the participants in coping, managing and surviving the illness was humbling and gave a picture of cancer experiences in a black community that has not been examined or identified in previous research

The role of black men caring for their women has not been addressed in other literature but was evident as an implied feature of widowers' narratives. This was an area they themselves did not articulate, possibly because they did not see themselves as doing anything special other than caring for a loved one. However, I marked this common theme as an important positive counter action to the often negative popular media and policy images of black men in relation to family responsibility

Adapting Bury's (1997) and Hydén's (2001) frameworks enabled specific exploration of illness narratives in which ethnicity was a key factor across all the narrative themes. Gaps in both frameworks were identified; if addressed they could expand those frameworks, through further consideration of multicultural and minority ethnic illness narratives. In addition, the impact of illness on carers is not explicitly addressed in Hydén and Bury's typologies. In this research, carer narratives were informative in addressing the wider impact of illness beyond the individual with cancer. An in-depth analysis of the narratives highlighted the complex relationships between narrators and healthcare professionals, interlinked to culture, ethnicity, 'race' and cancer experiences.

SECTION FOUR: DISCUSSION AND

CONCLUSIONS

CHAPTER 7 – DISCUSSION AND CONCLUSIONS

7.0 Introduction

In summarising Mishler's (1986) observations, Riessman (1992, p.223) states:

> Narrative analysis is particularly well suited to understanding the process of making sense of difficult experiences because it lays bare the interpretive work narrators do in collaboration with listeners.

This chapter presents my interpretative elicitations of higher-level meanings from the analysis, providing an insight into: narrators overall experiences of cancer healthcare and how those experiences have a personal and socio-cultural context. The chapter presents a deeper insight into the findings presented in Chapter Five and Chapter Six, of behaviours and actions not recognised by the narrators themselves, but which were an integral part of their narrative. In addition, the chapter also presents my findings' in relation to prior research, pointing to the areas where these findings suggest new conclusions around BME people's experiences of cancer services. Finally, this Discussion and Conclusions chapter explores some of the implications of this study for policy and research in its penultimate section, 'Implications and suggested actions for practice'.

Murray's (2000) levels of analysis (personal, interpersonal, socio-political, positional) were drawn on below to provide an integrated approach in discussing the findings. I chose this approach to discuss the findings as the narratives straddle these levels and hence Murray's work provided a means of connecting interpretations. Interconnections were evident between and within the narrative themes. To synthesise these interconnections, I created the following interpretative meanings which could usefully be described as

operating at the levels Murray identifies: culture, ethnicity, race (socio-political level); religion and the power of church leaders (socio-political level); courage, strength and resilience (personal level); black men as carers (socio-political and personal levels); talking to 'me', the carer (personal level); 'I' as the researcher: sharing cultures (interpersonal and positional levels). My reflections as discussed in Chapter Four, subsection 4.8 (p.137) is another representation of Murray's positional level.

7.1 Culture, Ethnicity and Race

African and African-Caribbean communities have a shared history and similarities in experiences of being black in the UK, but as communities they are different, an issue rarely explicitly acknowledged in research. They each have different cultures, traditions, folklores and societal norms and acknowledging these differences in relation to cancer is of interest and important to identify effective cancer health strategies to better inform these communities. Ajose-Adeogun and Qureshi (2012) recognised differences in how Africans and African-Caribbeans viewed cancer, reporting Africans were less likely to talk about cancer in comparison to African-Caribbeans, but they did not explore why. My research has delved further, drawing out some of the dissimilarities and similarities between and within the African and African-Caribbean narratives and their views on their respective communities in the interconnections between cultural beliefs and behaviour related to cancer.

Discussing cancer as individuals the narrators in this study were open and candid. However, when their narratives related to the wider communities with

regard to talking about cancer, there were differences in how they perceived their respective community talking about cancer. Predominately the African-Caribbean and Ghanaian narrators perceived there was more openness in talking about cancer in their communities; however, the Nigerian account resonated with studies on South East Asian communities and studies involving East African communities in London (Abdullahi and colleagues, 2009; Karbani and colleagues, 2011) and the work of Thomas and colleagues (2005). These studies and the Nigerian narrator's account of her community highlighted the potential ramifications for an individual with cancer and their family and therefore cancer was a taboo subject. The Nigerian's narrative account pointed to the belief that in some way attending for cervical or breast screening meant 'looking for something' which implied some perceived promiscuous behaviour.

Silence creates a phenomenon of interpersonal isolation, feelings of stress, shame and fears of being ostracised from the community were shared by the Nigerian narrator, and although generalisations cannot be made from one participant's account, it is the truth, as she believes it to be and parallels the findings of the previous research, (Littlewood and Elias, 2000). These cultural beliefs accentuate difficulties in talking about cancer, conducting self-examination and undertaking health-promoting activities such as screening, illustrating how entrenched cultural beliefs can impact on health behaviour which healthcare professionals need to understand. The findings of this research both concur with and are in contrast to the work of Littlewood and Elias (2000). Unlike their study, all the women in my study did not share the

fear of being ostracised from their communities; support was from various sources; family, friends, church, black cancer support groups and other patients who intimately understood the battles of overcoming cancer.

The narratives revealed how culture transcended across a number of areas (cancer screening, access to cancer services, communication), highlighting some different perspectives on culture and illness reported in earlier research (Box, 1998, Pfeffer, 2004) as well as corroborating with other studies (Abdullahi and colleagues, 2009; Koffman and Higginson, 2001). The narratives demonstrated how life events were different for each narrator who was diagnosed with cancer and how those events shaped responses to their illness experience and through narration generated different perspectives to known socio-cultural and ethnic challenges with healthcare.

Clearly, how the diagnosis of cancer was given to the narrator determined the narrator's response. Some narrators were shocked and entered into a cycle of many mixed emotions in which the fear of their future was put into suspension and the disruption in their life which then ensued. Loss of control referred to powerlessness, helplessness and the impact of the disease on the body. Confusion was an important contributor to distress when receiving bad news, the lack of clarity in explaining issues led to misunderstanding, a situation evident in some narratives: Sara's father was told he had 'a growth' and did not understand the association between growth and possible cancer; Ngozi was given the 'all clear' from the surgeon only to receive a letter from the oncology team; Joseph was fearful of hospice care for his wife, as this was

seen as a place with no hope because its services were not explained. Practitioners use words such as 'inoffensive' which mean very little without explanation. Failure of healthcare professionals to communicate effectively as illustrated in some of the narratives, created a vacuum and a potential opportunity for healthcare practitioners to fall back on stereotypical views.

Narratives presented contrasting skills of healthcare professionals' abilities to listen and to 'hear' what participants had to say. These are critical interpersonal skills of communication healthcare practitioners require as essential tools to gain an understanding of the person's story, to ascertain the person's understanding of their diagnosis of cancer and the effects of the illness as well as the impact of treatment on the ability of the person to carry out daily living activities. Lack of engagement in not asking questions may present as a lack of interest on the part of the individual by healthcare practitioners. However, past experiences of the health service by an individual, as well as their age and the deference some elders may bestow on clinicians, can hinder their abilities to question clinicians. This is also an issue for older white patients, particularly those with lower socio-economic status too but, being stereotyped by healthcare practitioners due to age and ethnicity, places black elders in a different situation.

Narrators articulated the breadth and scale of inextricable challenges cancer causes to the spiritual, psychological, physical and emotional domains of their life. The essentiality of health professionals having the skills, capacity and patience to listen to and understand the distress of narrators was a consistent

feature in the narratives. Difficulty with managing the emotional pain of diagnosis and side effects of treatment was least well managed by healthcare professionals. This was particularly the case for those participants whose treatment impacted on fertility and sexuality. There was no mention in the narratives of support from health professionals through this difficult time, yet it was a profound focus in the narratives of two narrators, Ebony and Sharon. The impact of impotency for the Michael was difficult for him to comprehend and adjust to loss of masculinity and these were issues of care not addressed by healthcare professionals.

Migration, ethnicity and race are features which played a part in some of the narratives and Becker and Newsom (2003), Nanton and Dale (2011) demonstrated the importance of historical events which impact on health and illness behaviour. Whereas Becker and Newsom (2003) refer to slavery and its historical significance in African-American history, which still has its influential roots in American societal structures, Nanton and Dale (2011) refer to the history of migration from the Caribbean to the UK. Elkan (2007) refers to the need to recognise the effects of migration on health and family structure. In my study, the potential impact of migration was of interest as none of the narrators were born in the United Kingdom, but have lived in the UK (with the exception of Sharon) for more than 20 years and hence the impact of life experiences, the level of acculturation, adjustments to a different life and challenges of acceptance by the host community were implicit in narratives when referring to trust, communication and respect.

There is a plethora of literature on breast cancer, Banning (2011) Okobia and colleagues (2006), Karbani and colleagues (2011), but an area which has not been developed in literature but was a significant issue uncovered in my research, was the interrelation between culture and breast self-examination; in particular, the acceptance of conducting breast self-examination. This research has been the first in the UK to make an associated link between cultural issues and conducting breast self-examination in relation to African and African-Caribbean women. Some women spoke of the action as being uncomfortable perceiving it as abnormal to 'touch yourself' (Jennifer) in such a purposeful manner. This is a complex phenomenon presented in the narratives in which socio-cultural attitudes affect health-promoting behaviour and is exacerbated by perceived low levels of awareness regarding the value of breast self-examination. The narratives have drawn attention to the lack of guidance on how to conduct breast self-examination, contradicting Pfeffer's (2004) study suggesting the education of women to undertake breast self-examination is the norm.

In addition, narratives point to not only challenges of cultural acceptance of performing breast self-examination but to the existence of a sense of inevitability; if breast cancer occurs that there is little that can be done. Arguably this perspective suggests there is an external locus of control in which women perceive themselves to be powerless therefore whatever the outcome is going to be it has already been 'decided'. Therefore attending for cancer screening or conducting self-breast examination will make no difference to the outcome. Fatalism was not a concept narrators subscribed to

in this research, but some narrators discussed fatalism in respect of its existence having some effect on the behaviour of some individuals in the wider communities. Several narrative accounts suggested cancer was seen by some women in the wider community as a death sentence and interpreting their narratives they appear to rationalise such opinions based on a number of factors: experiences of high mortalities in their country of origin, level of education and lack of information of symptoms associated with possible cancer diagnosis and lack of knowledge on developments in cancer treatments. Living in the UK, entrenched cultural norms and experiences coupled with lack of awareness of accessing health preventative measures may still make individuals believe cancer is always fatal.

The women in my study referred to having an awareness of breast self-examination; they had conducted breast self-examination and attended mammogram appointments in the past. However, when they spoke about the wider community, the majority believed information on breast screening and the importance of breast self-examination was either lacking or not targeted well enough at black women. Of particular concern was the lack of culturally sensitive imagery on breast screening, which inadvertently perpetuates the view, the narratives suggest, of the wider community that breast cancer is not a significant prevalent illness among black women. The women also highlighted that information on the rationale for screening was lacking, a finding also in Box (1998) study. Another aspect of breast health monitoring is accessing family history clinics for women with a family history of breast cancer. From the narratives there appeared to be inconsistencies in women

being referred to these clinics. Three women in this study had a family history of breast cancer but only one was referred to a family history clinic at her insistence and it was through such follow-up her cancer was identified. This illustrated the value of such a service which appeared to be denied to the other women.

Culture provides a medium for the different ways in which individuals understand cancer, how they explain its occurrence and offer a basis for their attitudes towards cancer and life. Cultural differences between the healthcare practitioner and the patient can be a breeding ground for conflict and cultural insensitivity leading to a lack of service engagement among users, an issue reflected in some narrative accounts. Understanding cultural norms in which, for example, admitting to physical pain is seen as weakness, requires clinical skills and cultural knowledge by healthcare practitioners to address the issue (for example, pain as narrated by Sara about her father's care) whilst maintaining the person's dignity. The existence of differences in the way pain is experienced by ethnic minorities (Koffman and colleagues 2008b) has been acknowledged, but this knowledge is not well used in practice as illustrated in my research. Stoicism can be common in older Caribbean men and is a behaviour others have commented on (Nanton and Dale, 2011). This can be a difficult aspect of care but not impossible when skills in understanding cultural behaviour in illness are applied to communication, pain assessment and the use of appropriate analgesia administration.

Thomas and colleagues (2009) evidenced ethnicity and therefore 'race' was a significant variable in patient satisfaction with cancer services. Racism as highlighted by Karlsen (2007), can and is associated with ill health (depression, hypertension, stress) and class-based discrimination interacts with racism in a complex manner as amplified by some of the narrators, which for some culminated in negative experiences; ('I really felt if I was a different colour she would have treated me differently' (Kahn) and ('they didn't consider my needs' (Ebony). For others there was a conflicting dilemma in considering whether negative treatment was due to class or race; 'I would like to think it was a difference in social class rather than race which makes any difference in care' (Ngozi). Positive experiences were described by other narrators in my study ('I got top notch treatment' (Sharon). Understanding and unlocking these diverse experiences, reflect the significance of these socially determined constructs and their ability to inform attitudes, which can compound interrelationships and capacity to cope and adjust to illness.

The majority of narratives suggested racism was not a significant factor in their care which to some extent may demonstrate positive attempts in cancer care services to be more engaging with the African and African-Caribbean communities. However, all narrators acknowledged that racism can be an issue in healthcare and must be addressed at all levels of care. For those narrators for whom racism was a very pertinent part of their narrative, perceived racism was reflected in ethnocentric attitudes and behaviours. Using a narrative approach provided opportunities to identify different perspective on ethnicity culture and 'race', which reflected both positive and

negative counter-narratives to dominant narratives on race, health and illness behaviour.

7.2 Religion: testing faith and the power of religious leaders

Religiosity is interwoven with culture, communication and relationships between individuals. It was a fundamental act which engendered positive attitudes and lessening any sense of isolation, 'I knew he was with me' (Sharon). Religion can be entrenched in traditions and folklore, but individuals can have different perspectives on the same religious belief system, affecting their behaviour in illness. This study identified the complex relationships between and within religious practices indicating the importance of healthcare professionals to firstly be cognisant of how much power religion can play in the lives of African and African-Caribbeans and secondly to understand the individuality of the person in how they practise their faith.

Being part of a religious community offers not only emotional but practical support, encouragement and gives hope (Henderson and Davis, 2003). The significance of religion and spirituality as a basis for emotional support during challenging times with ill health has been reviewed in earlier papers (Koffman and colleagues, 2008a; Nanton and Dale, 2011; Redman and colleagues, 2008). However, narratives in my research highlighted some differences in this genre. Most significant was the power of pastors and their relationship with followers in influencing health and illness behaviour, particularly in relation to cancer. There was a distinct difference in how church leaders were

portrayed between Nigerian, Ghanaian and African-Caribbean narrators which previous research has not addressed.

When narrators reflected on the behaviour of their wider community, there were differences in how pastors' authority was considered and how much weight was given to the words spoken by church ministers as to whether they were a vehicle through which God 'spoke'. This notion of the level of perceived power was held strongest by the Nigerian narrator and this belief coupled with culture and taboo to discuss cancer can impact on the individual making decisions on health behaviour. 'The way I've experienced things, with regard to church, is the fact that many of us, appropriate Pastors to be God.' (Ngozi).

Praying was a powerful medium to be close to God; however, this was construed as having both a positive or negative impact on health-seeking behaviour. In some narrative accounts, this was especially the case when the pastor advocates prayer as the only answer to recovery from illness and hence the depth of praying is testimony to that individual's level of belief in God. As a consequence, there can almost be a sense of 'blaming' the individual (a potential perception created by the pastor's actions) for any worsening of their situation because they have not prayed enough and hence lacking in faith in God's 'abilities'. In contrast, other narratives depicted how the pastor guided the narrators through their decision-making, placing no blame on the individual or creating a sense of fear of being considered lacking in faith because of a decision taken to access cancer screening services or

accept cancer treatment. There was a positive association in the relationship between church leaders and decision-making on health seeking behaviour by Ghanaian and African-Caribbean narrators, which was in contrast with the Nigerian narrative.

None of the participants 'blamed' God for their having cancer and this attitude was also found in studies by Becker and Newsom (2005); Henderson and colleagues (2003). In my study, the Ghanaian and Caribbean narrators did not project any negativity towards their religion. The Nigerian narrator spoke positively about religion in relation to herself, but when she widened her narrative to her experiences of Nigerian Pentecostal worshippers, her account resonated with Karbani and colleagues (2011) findings on South Asian women women's on breast screening and breast cancer and the study of Abdullahi et al. (2009) concerning Somali women's perceptions about cervical screening, in which cancer was seen as punishment for wrongdoing, a 'sign' of having transgressed some socio-culturally agreed normative behaviour, setting in motion the behaviour of silence and the emotions of fear and shame.

Illness prompted an increased emphasis on belief in God and spirituality was at the heart of surviving cancer and the onslaught of side effects caused by the treatment. God as a resource for healing and how some narrators 'communicated' with God through prayer, had a comforting and uplifting effect, removing the burden of the illness from themselves to God. Faith reduced the feeling of loss of control that cancer created ('I just handed it [the

cancer] over to God' (Sharon). Drawing on scriptures to overcome adversity and cope with treatment was a common feature of the narratives. Spirituality and religion were building blocks for hope from which narratives about their cancer experiences were framed. They offered psychological benefits and my findings are in contrast to McCoubrie and Davies (2006) who suggested religion did not have any significance in psychological wellbeing.

Narratives attested to the strength of God and many narrators stated they lived their life through religion; it shaped and encompassed who they were as a person and how they viewed their illness. Living life underpinned by their belief, their recovery was an affirmation of their faith in God. My findings concurred with the conclusions of Henderson and colleagues (2003) in their study comparing religion and spirituality between black and white populations. They concluded spirituality was less important to white participants than it was in the lives of black participants. Furthermore, Koffman and colleagues (2008a) identified religion was important for both black and white patients but culture shaped the difference in the expression of religious beliefs which was greater amongst black participants in their study.

For some narrators, God demonstrated his powers of healing and 'his' power of helping to defy the odds; in Joseph's narrative he believed their faith kept his wife alive longer than doctors predicted; Mary saw herself as a testimony to God's work and to be an inspiration to others. Sharon viewed her situation as a demonstration of God's healing power and Ngozi welcomed the gift of God in developing skills and technology to improve health. These findings

reflected meanings narrators gave to cancer and how they recaptured some control in their lives.

All but one narrator (Kahn) drew heavily on their religion and it was an aspect of care when the narrators spoke about their hospital care, which was not given significant focus by healthcare practitioners. Narrators were asked by healthcare practitioners which religion they practised, but this represented only a cursory interest in the narrator's religion since healthcare professionals as the narratives suggest made no use of that information in how the healthcare professional cared for the narrator. The National Institute of Health and Clinical Excellence (2004) recommend accurate and timely evaluation of religious and spiritual needs of individuals being cared for in hospital settings. However, evidence of this in practice is very limited in the UK and it primarily focuses on the indigenous population.

Narrators wanted their religious beliefs to be considered in their care and although previous research (Curtis and Lawson, 2000; Thomas and colleagues, 2005) had concluded religion is important in healthcare; my study makes the associated link from the narratives between collecting information on religion and the necessity of framing it within delivery of care. By creating opportunities with questions aimed at facilitating an individual's expressions of their illness which may include religious and spiritual beliefs, healthcare professionals can gain insights into how those beliefs shape perceptions the patient may have about their illness, its symptoms and hence influence the care being planned, thus providing more culturally competent care.

7.3. Courage, strength and resilience

Within the narrative theme, 'reliving their diagnosis', the attributes, courage, strength and resilience were striking in narratives from both carers and those narrators who had a cancer diagnosis. Their stories demonstrated how they coped with and adapted to a life which had cancer as an unwanted 'visitor'. Narratives alluded to how narrators managed cancer and its potential consequences, reflecting their abilities to recoup some form in equilibrium to lives, disrupted by cancer. Courage, strength and resilience are attributes which have been rarely addressed in UK literature in relation to African and African-Caribbean communities, but have received some attention in North American literature (Becker and Newsom, 2003). These three characteristics were evidently tied up with coping within the narratives. Coping is a concept which has various definitions and to which is ascribed a range of meanings and Becker and Newsom (2003) conclude in their summation in relation to 'resilience' as being a culturally specific paradigm; meaning socially constructed negative events (racism for example), creates a situation in which to overcome those obstacles, individuals build psychological resources as a means to cope with life adversities. Thus, when considering life events, which are shaped by historical racial encounters, resilience' cannot be ignored.

As outlined in the Chapter Two, in the UK Nanton and Dale's (2011) study of Caribbean men diagnosed with prostate cancer, drew attention to how the attitudes of those men depicted strength of character in adapting to, coping with and managing their illness, which was shaped in part by historical life events as well as by negative experiences of cancer services. Becker and

Newsom's (2003) and Nanton and Dale's (2011) studies focused on either older black people or only black males, whereas this study had a mix of gender and age groups, highlighting the existence of courage, strength, resilience across the spectrums of age and gender.

The courage shown by the women in this thesis when 'reliving their diagnosis' encapsulated the concept by Mullings (2005) called 'Sojourner Syndrome'. It relates to behavioural strategies adopted by black women to survive adversity and the 'Sojourner Syndrome' demonstrated by the women in my study were varied: in what they said ('I am not going to let it dictate my life' (June), how they spoke (with passion and determination in their voice and gestures such as shaking of the head, sitting more upright in a defiant manner), actions some had taken: talking to others about their illness (Jennifer, Mary, Ebony), not being around negative people (Ngozi), having a focus on something or someone (Sharon, Lorna), willpower and drawing on their faith or spirituality (all the women). These behaviours gave an insight into their inner strength of managing adversity created by cancer.

In addition, the actions demonstrated how courage and resilience enabled narrators, according to their own accounts, to cope with negative consequences of interrelations between themselves and healthcare practitioners. 'Having a focus' and 'will power' are not uncommon endeavours found or reported in the white community, but here those behaviours and reports, I would suggest, occur against the background of an additional burden of overcoming racism and indifference from healthcare professionals,

an issue for some of the narrators in my study and reported elsewhere (Curtis and Lawson, 2000; Elkan, 2007). The frankness and openness with which Michael spoke about his illness is exceptional and atypical within his Rastafarian community, particularly discussing incontinence and impotency. His aspiration was to speak out about prostate cancer, wanting to encourage other men to talk about cancer to help their community be better informed.

A cancer diagnosis can shatter the ontological security of life's journey and considering the behaviour of narrators in this research from a societal perspective, especially for the African women and the Rastafarian male narrator, their candour about their illness would suggest they were breaking through the wall of silence about cancer. By telling their story, it appeared they wanted to address the misconceptions created in part by the silence within their communities, as well as by cultural dogma and folklores about cancer. Understanding how African and African-Caribbean people cope, how they manage the day-to-day challenges of cancer is fundamentally important for healthcare professionals in order to harness those skills to support the individual.

Narrators focussed on reliving their lives; they lifted themselves out of any sense of negative thinking about their illness and kept a focus on what were goals to achieve; being a mother, attending graduation, refocusing on priorities and for all narrators, with the exception of one narrator (Kahn), spirituality was their foundation. Reflecting on the narrators' positivity, I deliberated on the possible association of time lag between diagnosis and

taking part in the study. None of the narrators were receiving further treatment; they had infrequent hospital check-ups and therefore could feel positive about life. Temporality was therefore an important factor not only in recovery but attaining emotional equilibrium.

7.4 Talking to 'me', the carer

An unexpected outcome from the research was the value given by carers in taking part in the study. For those with cancer it was an opportunity to provide some semblance of order to a chaotic world caused by disease, but for carers 'telling' their story was cathartic. Research itself is not therapy, but it can be therapeutic and narratives from carers suggested there was 'therapeutic' value in telling their stories; 'I was a bit nervous of doing this [taking part in the study] but I am so glad I did now. Just talking has lifted weight I didn't really know I was carrying until now' (Sara). 'I didn't think I was going to get anything out of this, but it has made me feel maybe I did do things right for her' (Joseph).

In conducting the study, I attempted to create the right environment for interviews and giving narrators the opportunity to choose where to be interviewed gave them control and comfort in choosing a familiar place. Two carers were interviewed in their homes, another in her office at work and she chose to divert telephone calls and her pager was covered by a colleague for the duration of the two-hour interview.

Participating in the study provided an opportunity for the carers to be heard; 'voicing' their anxieties, being able to have a dialogue on what was it like for them as a husband and daughter. Having an opportunity to be the 'centre of attention' with a stranger they did not have to be concerned with being emotional, or in the case of Sara (the specialist nurse), feeling she had to have all the answers. Carers referred to the opportunity of being able to be open about their feelings, questioning had they done enough or why did they not know of a particular course of action until too late; the times of struggling with healthcare professionals, and balancing caring duties with day-to-day work, taking time off work then losing one's job and falling into the quagmire of social services and benefits systems leading to at times an unwelcome intrusion into their lives, were profound issues different carers narratives presented.

There are generic issues which are the same for all carers including the white community (concerns about their loved one surviving, financial constraints, role changes within the family, dealing with death). However, as illustrated in this study, for African and African-Caribbean carers considerations of the cultural impact of the diagnosis cannot be ignored. None of the carers, for example, knew of the existence of black cancer charities until taking part in the study and two carers indicated knowing of them could have been beneficial at the time of caring for their loved one. But most of all, as the carers' narratives suggested, apart from clinical support by healthcares, creating an environment conducive to listening is the best investment in cancer care a health practitioner can give to carers.

7.5 Black men as carers

The role of women as carers, in taking responsibility for the health and welfare of the family has been previously documented (Jones, 2010). Also in Nanton and Dale's (2011) research women were instrumental in being the vanguard for their family's health. The role of men, particularly black men, as carers for women with cancer has not been previously explored, yet the widowers' narratives in caring for their wives, coping with and adjusting to the loss of their wives articulated a redefining of roles within the family. This study presented a contrasting perspective of the negative images at time portrayed about black men. Joseph cared for his wife at home during the later stages of Rosie's illness. Community care services were organised but they rarely used the services of the district nurse, the palliative care nurse or Twilight services. The older widower's story (Joseph) was one of constant companionship to Rosie, managing her personal care and, refusing to have her placed in a hospice depicted strength of character in the face of his wife dying at home. Joseph refers to constant support by his children which he suggested gave both him and Rosie quality time together.

As with Kahn (the younger widower) the social support network was pivotal as an anchor for providing him with help. Kahn had a good network of friends who supported him with childcare and helping with preparing meals. However, adjusting to single parenthood, taking responsibility for the health of his child, not wanting outside help, being in control, the need to be seen to be coping, the fear of starting a new relationship, were striking features of Kahn's narrative. The socio-cultural context of the black men within the media tends

to present them as being irresponsible and this study presented a counter-narrative on the positive image of black men as carers, which is not examined in previous research.

7.6 'I' as the researcher: sharing cultures

Being an African Caribbean, writing about African and African-Caribbean experiences of cancer services in London meant acknowledging my role as both researcher and a member of the black community, taking responsibility for the narratives used to present an analysis of experiences. The very nature of the chosen narrative approach (dialogic analysis) made me an active contributor to the development of stories shared within the research context, but I am responsible for the interpretative meaning and (re)presentation of those narratives. Using dialogic analysis provided me with the opportunity to be immersed in the research process in the co-construction of those narratives.

Subjectivity was an element in interpreting the data which could create a challenge with validity. It could be considered that being a member of the African-Caribbean community under research compromises the value and validity of the findings. However, thoughtful selection of narratives with rationale for their choice, describing how I arrived at my interpretations, explaining what each narrative aimed to explore, were actions aimed at addressing the issue of validity. Being part of the community, sharing a culture I saw as a resource and was not a distraction to the research process. The trustworthiness of the stories from the narrators stems from what I considered

to be the sense the stories made and the commonalities independently articulated when analysing the narratives together.

Being an African-Caribbean woman, but one who also has a special interest in cancer both from a personal and professional perspective and drawing on learned research skills, as well as having familiarity with the culture, was an asset, dictating the shaping of the research. Narrators knew I would have an understanding of paralinguistic cues which captured at times specific points being made, thereby creating an atmosphere of partnership between myself and the narrators. Concurring with Goss and Goss (1995, p.144):

> When you go into any culture, I don't care what the culture is, you have to go in with some humility. You have to understand the language, and by that I do not mean what we speak. You've got to understand the language, the interior language of the people. You've got to be able to enter their philosophy, their worldview. You've got to speak both the spoken language and the meta-language of the people.

This was the premise I considered when interviewing African narrators. I was aware that culture-based differences in oral traditions between me and narrators could have led to problems with data collection and interpretation; therefore, I frequently checked back with narrators during the interview for verification of whether I had understood correctly the points being made. I gained significant insight in understanding the cultural traditions and norms of their communities some of which resonated with African-Caribbean communities. Discovering similarities in health beliefs between the Ghanaian and African-Caribbean narrators was enlightening and illustrates Dein's (2004, p.119) point that no culture is pure and that 'boundaries between cultural groups are often unclear'.

7.7 Personal narratives and their use in research with black communities

African and African-Caribbean communities have a rich tradition in oral history, which is an untapped resource in UK research. Understanding the values and experiences that shape the tradition is essential to understanding the stories shared by African and African-Caribbean people in the research context. As with other authors such as Banks-Wallace (2002), I understood the importance of how historical and immediate contexts and cultural norms are assumed to have major influences in how a story is created, how it is shared and thus understanding the impact of those factors was aided by using an analytical framework (dialogic analysis), underpinned by theory (narrative research) to capture the detail from the narratives to potentially generate new knowledge. There was an excitement in gaining an insight into how narrators transform specific experiences into wisdom stories that they shared and there was a sense of altruism by the narrators in wanting others to learn from their experience for their betterment.

As a qualitative research method, narrative research was valuable in enabling an understanding of issues that affect African and African-Caribbean communities in relation to cancer and receiving cancer services. Understanding the value of oral traditions of African and African-Caribbean communities revealed the depth of their lived experience and how those experiences shape their behaviour in relation to health and illness. Furthermore, identifying counter-narratives in illness stories, particularly in relation to culture, 'race' and ethnicity is an important focus because of the

power differentials between the clinician and the narrator. This is not explicity addressed in Bury (2001) and Hydén (1997) typologies, yet it is important in the context of racialisation and power.

7.8 Conclusion

As highlighted in Chapter Two, the majority of UK research related to cancer in the non-white population is focused on South Asian communities (Elkan, 2007), or on ethnic minorities as a group (Szczepura, 2005), or on a single cancer site – breast, cervical, prostate (Chinegwundoh and colleagues, 2005; Scanlon, 2005). Some of the findings in my study allude to similarities with research previously reviewed, but this study has discovered new knowledge on African and African-Caribbean experiences of cancer services in London, thereby building on current literature on these communities living with cancer in the UK. The narratives verified culture and ethnicity as being determining factors impacting on individuals' responses to cancer, what they believe/perceive about cancer, how they undertake health seeking behaviour and how they engage with healthcare professionals

By focusing on African and African-Caribbean communities, I wanted to explore experiences of cancer services and framed the research questions on: what factors affected their experiences of cancer services? How culture, ethnicity and societal factors influenced the experiences? How did those factors influence the stories they told and the way they told them? What were good and bad practices which affected their experiences? What is the value of

narrative approach in research related to cancer focused on African and African Caribbeans?

Murray's (2000) levels of analysis were used to provide an integrated approach to the discussion which enabled an insight into how the personal and socio-cultural dynamic interplay in the telling of stories and the forming of narratives. Setting narratives into narrative themes posed some challenges at not being able to look across at how one theme impacted on another (for example screening, religion and the power of pastors) and therefore using Murray's levels of analysis in the discussion allowed for crossing across themes, enabling the opportunity for demonstrating links and integration of narratives.

The narratives identified possible factors which reflected positive and negative experiences of Africans' and African-Caribbeans' engagement with healthcare services. Positive experiences of cancer services were articulated from the narratives, which included clinicians apologising for mistakes and clinicians creating an environment which encouraged a positive relationship between themselves and the narrator. Evidence of good practice of interrelations between clinicians and participants resonated with what Hurst and DasGupta (2003) termed 'clinical empathy' which they describe as having three components:

> a cognitive component in which the clinician "enters" the perspective of the patient, an emotional component in which the clinician puts him or herself in the place of the patients and finally an active component in which the clinician communicates understanding by checking back with the patient (2003, p3).

In particular June's and Ngozi's narratives on pages (158-159) and pages (204-205) respectively are examples of clinician's displaying 'clinical empathy' and narratives of Khan and Ebony, (pp.170-172,175-176 and pp. 200-203) where is was explicitly lacking. Some of the challenges narrators articulated have been addressed in previous research. These include: cultural insensitivity, lack of access to information on cancer services, lack of respect, feelings of powerlessness and vulnerability, but areas this research unearthed from the narratives not addressed elsewhere were: power of church leaders, breast self-examination and cultural issues associated with self-examination, acknowledgement of the heterogeneity of African and African-Caribbean communities and how that is played out in health-seeking behaviour and beliefs surrounding cancer, courage and resilience, areas which are rarely explicitly mentioned or recognised in earlier UK research, and the role black men played as carers, a subject virtually non-existent in health research.

Higginbottom and Serrant-Green (2005) stress the importance of researchers developing culturally sensitive research skills and this research has presented the use of narrative research as an effective tool to conduct research with African and African-Caribbean communities. I would also add gaining credibility and acceptance by the African and African-Caribbean narrators was equally as important as gaining approval from the university's ethics committee. Demonstrating a connectedness and familiarity with the narrators along with the professional position I held was a critical factor in being accepted by the narrators, which I appeared to achieve considering narrators allowed me access to other individuals, enabling snowballing to be successful. As a black woman, born in the UK to Jamaican parents, I was

also in a position to understand the challenges of navigating between two different cultural worlds, which at times placed me in a position of sharing cultural norms with some narrators.

Using dialogic analysis enabled narrators to talk about their experiences, providing rich data within a given context (that is, storytelling about cancer). I wanted to listen, not only to the individuals' narratives but sought to 'hear' how those narratives interconnected with each other. Individual stories were valuable in their ability to be informative and the interconnections between each story gave richness and validity to the research. In essence, this narrative approach afforded the opportunity to explore with narrators an illness that radically disrupts the present and reshapes thinking about the future.

Using a narrative approach allowed narrator involvement and the narrative accounts provided a much more in-depth analysis of individual experiences, not as easily achieved with telephone interviews, questionnaires or focus groups, which tend to concentrate on specific areas and may not allow for any broader interaction. Mishler (1986) puts this point in context when he discussed in his work the suppression of the narrative by other mainstream traditional forms of qualitative research. Counter-narratives were fruitful as they were deliberate directions some narrators took in what story they wanted to tell.

Conducting in-depth interviews as opposed to focus groups was appropriate for the topic and was also based on my cultural awareness in being cognisant of how some members of the black community feel about talking about illness.

Illness is considered by many in the black community, as a matter which is "private" and I did not consider focus groups as a useful medium for data collection, as there was a possibility of narrators not divulging valuable insights in the openness of a focus group; an issue Curtis and Lawson (2000) found in their study.

While undertaking this research I have had the privilege of being allowed 'entry' into other people's lives; a stranger wanting that person (the narrator) to return to an event in their life, which at times was painful, emotional, but enlightening to both the narrator and myself. Altruistic endeavours from narrators of wanting lessons to be learnt from mistakes were an important outcome they wanted to achieve by participating in the study. All the narrators were positive in wanting to talk about their experiences and were keen to share what was a turbulent disruptive period in their lives. How they told their stories could not be captured in any real sense through words and hence re-listening to recordings was valuable for me in giving memory and visualisation of points made at certain times in their interview which were emotional, created a significant turn in the story or remembering gestures which added to the richness of the words being spoken.

Neither Bury's (2001) nor Hydén's (1997) illness narrative typologies specifically incorporate ethnicity but their conceptual ideology allowed for such an adaptation. Ethnicity played a significant part in illness narratives in this study, demonstrating its relevance when narrators are from minority ethnic communities. Hence, building ethnicity into the combined adapted framework of these illness concepts, as illustrated in appendix 3 provided another

element to consider within illness narrative stories, enabling a greater integrated narrative analysis on illness experiences. Within a multicultural context of the UK society, issues such as migration and race are significant and for which the illness narratives frameworks need to be expanded to incorporate these elements.

In addition, neither typology explicitly considers the impact of illness on the carer and the adaptation of the typologies also demonstrated how they can be effectively used to gain rich stories from carers, enabling exploration of carers' narratives in caring for a loved one with cancer. Furthermore, by focusing on these two minority ethnic communities, it has partially addressed issues raised by Williams (2000) regarding the under researching of ethnicity and its impact on biographical disruption.

The narratives presented a complex interconnectedness between migration, cultural adaptation, racism, social class, gender and religion which coalesce in affecting and accepting healthcare interventions. In addition, what was also clear from the narratives is the recognition that African and African-Caribbean are not a homogenous group. Thus, addressing cultural preset attitudes about cancer requires sensitive, empathetic, non-judgemental attention by healthcare professionals.

Racism was not perceived as a factor that negatively impacted on experiences of cancer care by most participants, but all participants considered this was not an issue that has been fully addressed in healthcare. Clearly racism was a significant part in some narratives and therefore there can be no complacency in the drive to deliver equity and equality in cancer

care, ensuring dignity and compassion at a time when a life threatening disruptive event has occurred. Interwoven with race, culture and ethnicity is respect and dignity, which manifested itself through all the narratives as a central focal point of feeling valued.

Religion was a central focus for all but one of the narrators, many participants gaining immeasurable support from prayer and the companionship from fellow parishioners. Being aware of an African or African-Caribbean individual's level of participation in religious beliefs means having the opportunity to be more effective in delivery of care and the individual being more receptive to accepting advice and health interventions. The impact of religion was fundamental as a source of support, a means of coping with illness and healthcare professionals should ascertain when assessing patients how to capitalise and use the individual's faith to aid in providing more effective care for the patient. As Selman and colleagues (2009, p.43) points out:

> Cultural sensitivity entails recognising the complexity and range of culturally specific beliefs and practices, which are often related to religious or tribal affiliations. For example, syncretistic beliefs (e.g. faith in a Christian God combined with reverence of the ancestors) are common throughout sub-Saharan Africa, and may affect patients' and families' beliefs about illness and spiritual care needs.

However the caveat to this is recognising there are variations in how individuals practice religion, hence individualised assessment regarding faith and the individual's religiosity must be considered to avoid stereotyping and making assumptions. Harnessing church leaders' involvement in assisting with improving health seeking behaviour I consider important. Having their involvement in supporting health promoting behaviour can have positive results; this was a re-occurring solution by many narrators to help drive

forward positive health promotion guidance, particularly in relation to cancer screening. Thus making effective use of community links to improve cancer awareness to educate and inform, thereby dispelling myths and using less threatening venues such as churches can encourage and improve health-seeking behaviour.

7.9 Limitations of the study

The numbers of participants was no more than twelve and the study was focused only on one city. Widening the study to include another city to compare experiences of African and African-Caribbean communities may have alluded to variations in experiences.

Including a sample of white participants could have provided comparative analysis to ascertain similarities and differences in cancer care experiences. Increasing the number of men may have presented wider gender issues surrounding cancer care experiences. A focus group of healthcare professionals to ascertain both their experiences and perceptions of African and African-Caribbean individuals' behaviour in relation to cancer care could be combined with in-depth interviews of participants.

Using narrative research, posed the challenge of cross-referencing across themes, but Murray's (2000) levels of analysis provided a basis for addressing that issue.

7.10 Implications and suggested actions for practice

My study has alluded to some positive developments in cancer experiences from the narratives, but there remain experiences with cancer care for African and African-Caribbean Londoners, which raise the need for further research

to improve care. What has been highlighted are socio-cultural dynamics which significantly impact on seeking healthcare behaviour which requires greater understanding. The power of church leaders warrants further research attention. What shapes that power, what are its origins, does socio-economic status, level of education of the parishioners have any bearing on the perceived power of some church leaders? Further examination of what drives the resilience, strength and courage of Africans and African-Caribbeans and whether those drivers the same between the genders and age groups, could be explored.

The mortality rate of breast cancer as indicated in literature in Chapter One demonstrated the low prevalence but higher mortality rate of black women in comparison to white women both in the UK and North America. Breast self examination is an important element within breast screening interventions for early diagnosis, but as narratives have suggested there are cultural challenges with not only understanding what to do and how to do it, but also some reluctance to undertake breast self-examination by some black women. Exploration of these issues is fundamental to have a positive impact on reducing mortality.

Practical implications for improvements in practice from the study for caring for African and African-Caribbeans with cancer and the carers revolve around:

- Creating a "comfort zone" in consultations and nursing assessments can assist in individuals being put at ease when being questioned asking questions. Taking the opportunity to utilise information gained

about the person's religion can aid in appropriate interventions and referral.

- Better targeting of information, which dispels misconceptions, providing guidance to the African and African-Caribbean communities regarding common cancers, which affect them and addressing the importance of cancer screening which should be linked to information on survival rates with early diagnosis are actions required to support health-promoting behaviour. Use of simple imaginative interventions to impart information, apart from jargon free written documentation should include culturally relevant images, use of DVDs and information on black and minority ethnic voluntary groups as well as the main charities.

- Culturally appropriate healthcare events and seminars which should be delivered at venues which those communities actively attend – churches, mosques, black elder community groups and utilising resources such as working with libraries, local radio stations and local and black newspapers.

- Consistency is required in primary care of appropriate referral to family history clinics together with better communication between clinical departments and the patients.

Improvements in intercultural communications can harness a greater understanding of value systems and the cultural conations which encompass a deeper understanding of how cultural beliefs impact on health-seeking

behaviour. Practitioners must recognise coping strategies that African and African-Caribbean people use if holistic cancer care is to be achieved. Collaborative decision-making can be fundamental in engendering trust and satisfaction with services. Such a partnership can bring with it respect; however, as some narratives highlighted, this can only be achieved when healthcare professionals start from the premise of understanding the cultural background of the patient and genuinely engage with listening to the patient's narrative.

This research has presented the critical importance of recognising the cultural needs of these communities and hence the essentiality of healthcare professionals enhancing their awareness and skills in identifying and working with the individual if meaningful holistic cancer care is to be achieved. African and African-Caribbean communities are a significant part of the UK infrastructure and have a higher younger age population than the indigenous community. The incidence of cancer is expected to increase amongst these communities since the risk of cancer increases with age. It is therefore incumbent on healthcare professionals to harness a greater understanding of cultural differences between and with these groups as well as with the host culture if seamlessness of equity and equality is to be achieved in cancer care.

7.11 Final thoughts

Patient-centred care has been the government mantra providing a framework for a number of policies in relation to black and minority ethnic communities (as outlined in Chapter One). My study has alluded to some positive

developments in cancer experiences, but there remain experiences with cancer care for African and African-Caribbean Londoners, which demonstrates that much more is required for these communities to perceive equity and equality as standard within cancer care services.

'Cancer is a great equalizer' (Sharon). It pays no heed to race, gender, colour, age, wealth or social status. The diagnosis brings with it disruption, anxiety, fear in terms of future and physical pain. When these are placed in the milieu of socio-cultural interrelations of ethnicity, social class and race they fuel a complex dimension of how individuals manage cope, give meaning to cancer. Courage, defiance, positivity, overcoming adversity, deepening and re-connection to God are descriptors which depict the narratives.

The study has provided new insights and perspectives into the challenges as well as good practice from the narratives and has aimed to articulate a greater understanding and hence enhance the experiences of cancer care for these communities. This thesis has illustrated that like all patients with cancer, the cancer experience is an individual phenomenon but the narratives had demonstrated those experiences are bound up in historical, cultural, social, religious and spiritual perspectives.

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APPENDICES

APPENDIX 1

Most common languages spoken in London (adapted from Luddy, 2008).

<div style="background-color:#F5A800; padding:10px;">

English

Foreign languages in alphabetical order

Bengali
French
Gujarati
Hindi
Italian
Polish
Portuguese
Punjabi
Russian
Spanish

</div>

Appendix 2: Summary of articles reviewed (Full references supplied in the Reference section).

SUBSECTION	CANCER SCREENING					
Author (s) & year of publication & journal of publication	Title of research	Research method	Sample size	Sampling	Data collection	Key findings
Box, V (1998) Health Education Journal	Cervical screening: the knowledge and opinions of black and minority ethnic women and of health advocates in East London	Qualitative	194 (172 women, 11, health advocates and 11 facilitators	Purposive	Focus groups/interviews	Women either lacked awareness of screening services or held misconceptions about the smear test, better use of advocacy services. Language barriers hampered access to healthcare. Beliefs and attitudes which were culturally bound may impact on low attendance for screening. This was further compounded by fatalistic attitudes of some BME women.
McCaffery, K.et al (2003) British Journal of Cancer	Attitudes towards HPV testing: a qualitative study of beliefs among Indian, Pakistani, African-	Qualitative	71	Purposive	Focus groups	Lack of available information on HPV testing Upset, stigma and confusion Impact of testing positive for HPV Communicating unwanted messages Potential psychosocial harm

	Caribbean and white British women in the UK					
Chui, L (2004) Primary Health Care Research & Development	Minority ethnic women and cervical screening: a matter of action or research?	PAR	Total number not indicated	Women selected based on linguistic and cultural diversity and smear takers from six GP practices	Focus groups	Demonstrated PAR was an effective research method to gain insights into minority ethnic health issue and a useful agent of to support positive health promotion practices. Established identifying some causes for low uptake of screening by BME women, Women selected based on linguistic and cultural diversity and smear takers from six GP practices with low uptake of cervical screening which were in contrast to health practitioners' perceptions. Use of PAR brought about changes in attitudes and practices by smear takers leading to improved knowledge and increase in cervical screening uptake by BME women
Abdullahi, A. et al (2009) Public	Cervical screening:	Qualitative	50	Snowballing/Purposive	In-depth interviews and focus groups	Language barriers, fatalistic attitudes, lack of risk signs of

Health	perceptions and barriers to uptake among Somali women					cancer, embarrassment with FGM and how Western doctors would react. Better education and information, particularly oral information, better use of community advocates, improving access to culturally appropriate screening services.
Okobia, M.,N et al (2006) World Journal of Surgical Oncology	Knowledge, attitude and practice of Nigerian women towards breast cancer; A cross-sectional study	Quantitative	1000	Random	Interviewer-administered questionnaire	Level of knowledge about breast cancer was poorest among unprofessional women and those with a low level of education. They had limited knowledge regarding BSE. Recommendations for better community awareness by local health practitioners to improve the knowledge and experience of BSE to reduce the increase in breast cancer in Nigeria.
Pfeffer, N. (2004) Social Science & Medicine	Screening for breast cancer: candidacy and compliance	Qualitative	135	Purposeful	Focus groups	Candidacy and ethnicity were identified as similar constructs which impact on acceptance of breast screening healthcare. Gender differences of healthcare professionals were a concern linked to faith which impacted on attendance for breast screening.

Banning, M. (2011) European Journal of Oncology Nursing	Black women and breast health: A review of the literature	Literature review	15	1994-2009	Electronic database	Variety of views and perceptions on the risk of breast cancer -perceptions related to religion, spirituality, stigmatisation, lack of awareness of how to conduct BSE
Scanlon, K, (2004) Breast cancer care	An investigation into breast cancer related knowledge, beliefs, abs attitudes among women from minority ethnic groups living in London and Sheffield: A qualitative study	Qualitative	88	Convenience/snow balling	Focus groups	Poor knowledge of signs and symptoms as well as risk factors associated with breast cancer. Pessimistic attitudes towards cancer were found across both groups, but white women were more comfortable talking about cancer to close family and friends. All women believed early diagnosis was important and using breast screening services would be of values. However breast awareness campaigns were not reaching ethnic minority women.
Thomas et al (2005) International Journal of Palliative Nursing	Identification of the factors to effective uptake of breast, cervical and prostate cancer screening among Black	Qualitative	133 lay people 25 health professionals	Community based purposive	Focus groups	Inadequate uptake knowledge and uptake of cancer services Barriers to screening included language, cultural beliefs, unhelpful attitudes by healthcare professionals More access to female GPs

	and ethnic minority groups in Brent and Harrow Health Authority					Better community awareness information programmes Education of HCPs in cultural awareness.
Karbani, G. et al (2011) Asian Pacific Journal of Cancer Prevention	Culture, attitude and knowledge about breast cancer and preventative measures: a qualitative study of South Asian breast cancer patients in the UK	Qualitative	24 women and 15 significant others	Purposeful	In-depth interviews	Poor level of knowledge by the women about cancer and symptoms of breast cancer were observed. Cultural attitudes, beliefs impacted on women seeking healthcare. Potential social ramifications in being diagnosed with cancer. terminologies used by women caused communication challenges with healthcare professionals
Littlewood, J & Elias, E.(2000) Risk Decision and Policy	Risky shifts or shifting risk: African and African-Caribbean women's narratives on delay in seeking help for breast cancer	Qualitative	10	Purposeful	In-depth interviews	Awareness of breast screening services was evident but fear of isolation and losing social support from the church were significant factors in delay in seeking healthcare. There was a difference in the biomedical model of risk and the risk factors which the women presented.

SUBSECTION	ETHNICITY, ACCESS AND CANCER SERVICES					
Curtis, S & Lawson, K. (2000) Social Science and Medicine	Gender, ethnicity and self-reported health: the case of African-Caribbean populations in London	Quantitative & Qualitative	Quantitative sample - SAR from 1991 OPCS census (men - 9,823, women-10,361)	Purposive	Electronic databases Focus groups In-depth interviews	Psychosocial illness varies between Caribbean men and women Reservations in completing questionnaire Public and private health discourses Varying dimensions of health belief Social location: importance of 'race' and gender relations, Value of qualitative research
Szczepura, A. (2004) Postgraduate Medical Journal	Access to healthcare for ethnic minority populations	Literature review	101	Period not stipulated	Electronic database, desktop	Substantial research demonstrated evidence disparities exist in access to healthcare services for ethnic minorities; healthcare staff need to be linguistically as well as culturally competent to deliver services. Improved responsiveness to understanding health beliefs, practices and cultural needs is required to provide equitable access to healthcare for diverse populations.
Thomas, B.C et al (2009)	Patient ethnicity: a key predictor	Quantitative	653	Purposeful	Questionnaire	Ethnicity played a key factor satisfaction with cancer

| Ethnicity & Health | of cancer care satisfaction | | | | | services. Healthcare providers. Poverty, level of education and; language barriers may play an additional role in dissatisfaction with cancer services. |

SUBSECTION	MEETING CANCER HEALTHCARE NEED OF MINORITY ETHNIC COMMUNITIES					
Author (s) & year of publication & journal of publication	Title of research	Research method	Sample size	Sampling	Data collection	Key findings
Lodge, N. (2001) European Journal of Cancer Care	The identified needs of ethnic minority groups with cancer within the community: a review of the	Literature review	21	1993-1996	Electronic databases	Better ethnic monitoring required to generate better data from which to develop understanding incidence and mortality for BME communities. Greater consideration of BME needs

	literature					in relation to cancer can improve cancer care for all patients regardless of ethnicity. Education and training are important, better targeted health education strategies and interventions are important to improve access and awareness of services.
Elkan, R. et al (2007) European Journal of Cancer Care	The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature	Literature review	25	1990-2005	Electronic databases	Review highlighted significant concerns regarding comprehension and communication barriers, lack of awareness of services, failure of health professionals to recognise the importance of religion and cultural diversity. The paper challenges the outcome from some papers inferring lack of use of a service equates with lack of need. Evidence of some improvement in responding to BME health needs, but such initiatives are inconsistent and institutional racism is still evident.

Henderson, PD, & Davis, B. (2003) Oncology Nursing Forum	African American women coping with breast cancer: A qualitative analysis	Qualitative	66	Purposeful	Focus groups	Spirituality played an important part in coping with the diagnosis. Other factors which supported women was having positive thinking, belief in God, having a positive attitude, Black cancer support groups. Family support. Healthcare staff recognising coping strategies used by Black women should be recognised and harnessed by healthcare professionals
McCoubrie, R.C. & Davies, A.N (2006) Support Care Cancer	Is there a correlation between spirituality and anxiety and depression in patients with advanced cancer?	Quantitative	85	Purposeful	Structured questionnaire	Negative correlation was found between both anxiety and depression scores and overall well-being scores. There was no correlation between religion and psychological well-being. Patients with high existential/spiritual well-being were less likely to be anxious and depressed. Informal assessment can be a

|						
						mechanism for detecting clues of spiritual well-being in patients.
Chinegwundoh, F. et al. (2006) Journal Compilation – BJU International	Risk and presenting features of prostate cancer amongst African-Caribbean, South Asian and European men in North-east London	Quantitative	359	Population based	Histology, urology/oncology databases, Thames Cancer Registry	First study to conclusively demonstrate African-Caribbean men have a higher risk of developing prostate cancer compared to European and South Asian men in the UK. Findings comparable with North American and Caribbean studies
Nanton, V and Dale, J. (2011) European Journal of Cancer Care	'It don't make sense to worry too much': the experience of prostate cancer in African-Caribbean men in the UK	Qualitative	16	Snowballing	In-depth interviews	Better efforts in both giving and eliciting information. Better systematic referral and exchange between Sfrican-Cari9bbean men and the GP, hospital, social care and voluntary services. Negative assumptions and stereotyping by HCPs need to be addressed. Important to understand the impact of migration and life events as important factors which can effect responses and attitudes by BME in relation to illness and health.
Papadopoulos, I & Lees, S.	Cancer and communication:	Qualitative	6	Purposive	In-depth interviews	Similarities and differences in experiences of

(2004) European Journal of Cancer Care	similarities and differences of men with cancer from six different groups					communicating with healthcare professionals, family and friends and religion played in coping. The meaning ascribed to cancer differed between the men. Healthcare professionals needed to take account of communication issues to avoid cultural insensitivities.
Becker, G & Newsom, M. (2003) American Journal of Public Health	Socioeconomic status and dissatisfaction with healthcare among chronically ill African-Americans	Qualitative	60	Purposeful	In-depth interviews	Income affected healthcare experience and satisfaction with healthcare. Respondents categorised as being low SES had worse healthcare experience and indicated how poverty and its association with other socioeconomic has potential disastrous consequences on morbidity and mortality
Choumanova,I. et al (2006) The Breast Journal	Religion and spirituality in coping with breast cancer: perspectives of Chilean women	Qualitative	27	Purposeful	Semi-structured questionnaire	Religion and spirituality were important factors in helping women to cope with cancer. Religious practices predominately increased after diagnosis and was a resource fundamentally important to women as forms of coping mechanism as public health counselling services are unaffordable to

						many and limited in availability
Lanceley, A & Cox, C.L. (2007) European Journal of Cancer Care	Cancer information and support needs of statutory and voluntary sector staff working with people from ethnically diverse communities	Mixed mode	43 (10 patients/carers, 33 health and social care professionals)	Purposive	Focus groups and semi-structured interviews	Health and social care agencies working with BME communities had significant unmet educational needs to provide effective cancer information and support. Patients and carers were unaware of cancer services available. GP not consistently involved in the cancer care pathway and people who suspected they had cancer would access healthcare support late.
Ajose-Adeogun and Qureshi (2012) Paul's Cancer Support Centre.	Black & minority ethnic communities and cancer awareness in Wandsworth: a community based needs assessment	Qualitative	11	purposive	Semi-structured interviews.	Fatalistic attitudes based on personal experience. Generally low level of awareness of symptoms and signs of common cancers (breast, lung prostate) within the Black community. Differences between the communities in how they talk about cancer. Necessitated for better improved target information. Partnership working between churches and support groups to increase awareness.

SUBSECTION	PALLIATIVE CARE					
Redman , J.et al (2008) Diversity in Health & Social Care	Critical review of literature on ethnicity and health in relation to cancer and palliative care in the United Kingdom	Literature review	31	2000-2005	Electronic database	Range and quality of studies of the health & well-being of BME communities related to cancer and palliative care was patchy. Health professionals need to ensure good collation of ethnic minority data
Koffman, J. et al (2008) Palliative Medicine	Cultural meanings of pain: a qualitative study of Black Caribbean and White British patients with advanced cancer	Qualitative	28 African-Caribbean's participants 19 White participants	Purposeful	In-depth interviews	Pain was identified by groups as a challenge. The meaning of pain differed between the two groups with the African-Caribbean participants viewing pain either as a test of faith or punishment for transgression. Predominately the African-Caribbean gained strength from their religious beliefs and these meanings influenced the extent patients managed their pain. Pain assessment needs to accommodate patients' narratives about pain in order for effective care to be delivered.

Karim, K et al (2000) Palliative Medicine	Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctors' referral patterns	Qualitative	27 (12 GPs, 15 hospital consultants)	Random sampling	Semi-structured interviews	Under utilisation of day care abs inpatient hospice service by BME's in comparison to white patients. Doctors did refer BME for home care services. Reluctance of doctors to refer BME's for hospice care. Doctors believed palliative care services needed to be more sensitive to religious and spiritual needs of BME patients and staff should reflect the wider population.
Koffman, J and Higginson, I (2001) Palliative Medicine	Accounts of carers' satisfaction with health care at the end of life: a comparison of first generation black Caribbean's and white patient with advanced disease	Mixed mode	100 participants (50 black Caribbean's and 50 white participants)	Retrospective survey	Structured interviews	Evidence of good experiences by both ethnic groups was presented but the black Caribbean participants had greater dissatisfaction of healthcare across all healthcare settings. Specialist palliative care nurses were seen positively by black participants but few in number were referred to such services. Training and education in cultural awareness essential. Lack of empathy and difficulties with accessing information were challenges for black participants.

Murray's levels of analysis

Hydén's illness as narrative type

Bury's contingent & moral types
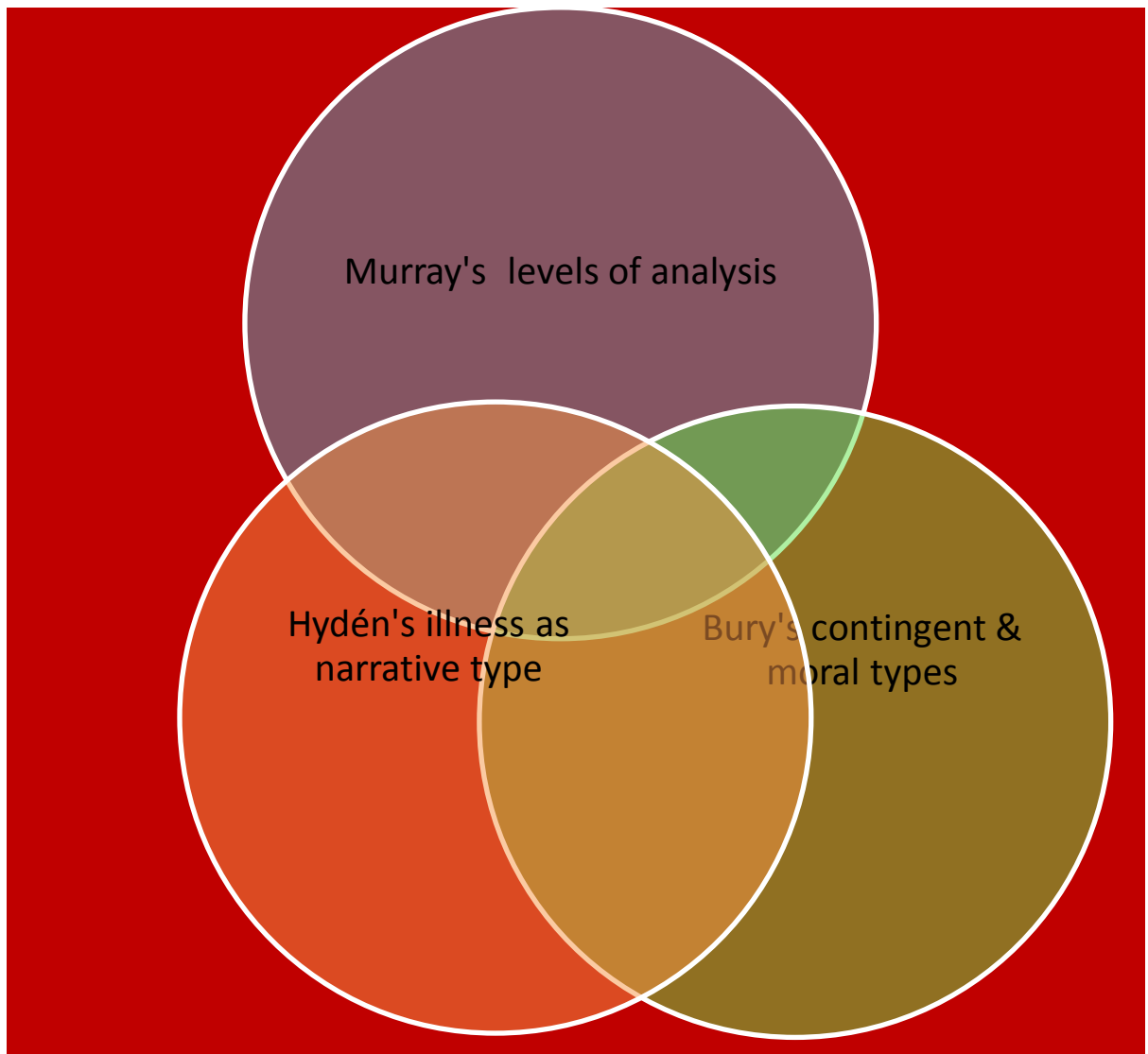
Brown's Narrative Framework

APPENDIX 4

Ms Marvelle Brown
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30 April 2009

Dear Marvelle

Re: Application for Ethical Approval No. FREC34/Mar09

Thank you for your application for approval. The Committee have considered your application and approved the research subject to satisfactory written clarification of the following:-

- The Committee identified concerns about the size of the 'sample' being proposed and its selection given the proposed methodology. A smaller 'purposive' sample would seem to be more appropriate. The Committee suggest that you discuss this further with your research advisor.

- Please provide a Consent Form and reformat the Participant Information Sheet into the standard TVU format.

- Further information is required about the support that is proposed for participants that may become distressed.

- Please also seek clarification from NRES that NHS ethical approval is not required and provide written confirmation of the response (email correspondence is acceptable).

Satisfactory clarification of the above will allow me to take Chair's action in approving the study.

I look forward to your written reply.

Yours sincerely

Heather Loveday
Principal Lecturer (Research)
Chair of the Faculty Research Review Committee
Heather Loveday

APPENDIX 5
RESEARCH ETHICAL APPROVAL LETTER

APPENDIX 6

African and Caribbean communities – experiences of cancer services in London

ARE YOU OF AFRICAN OR CARIBBEAN BACKGROUND?

HAVE YOU HAD PREVIOUS EXPERIENCES OF CANCER SERVICES- SCREENING? PREVIOUSLY HAD CANCER TREATMENT? RELATIVE/CARER OF SOMEONE WHO HAD A CANCER DIAGNOSIS?

IF SO, WOULD YOU TAKE PART IN A STUDY THAT WANTS TO HEAR ABOUT THOSE EXPERIENCES?

YOUR PARTICIPATION WOULD BE CONFIDENTIAL

THE STUDY WOULD INVOLVE A 1 –1½ HOUR INTERVIEW

FOR YOUR TIME A £20 MARKS AND SPENCER VOUCHER WILL BE OFFERED

FOR FURTHER INFORMATION, PLEASE CONTACT MARVELLE BROWN
marvelle.brown@tvu.ac.uk

APPENDIX 7

THAMES VALLEY UNIVERSITY
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Paragon House
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African and Caribbean Communities experiences of inequalities in cancer services

Interview Topic List

The interview frame below has been used extensively by Riessman, (1996, 2001, 2007) and is well documented.

This research does not involve a questionnaire or a fixed question format or order. It starts with an open question:

What has been your experience of cancer services?

The following fields are probed if not addresses spontaneously:

Primary care – GP

Hospital experiences

Access to information- sources of information

Access to services

Awareness of services/screening

Knowledge/use of voluntary organisations

Feelings

Emotions

Expectations

Support

Interviewees self-weight the interview, that is, they are able to decide to talk as much or as little about each area as they wish

Given time and other constraints (eg childcare, health) interviews are e⟩
no longer than two hours. Interviewees are, again, free to concentrate o
of research interest at the expense of others within this time fra

NHS

National Research Ethics Service

Moorfields & Whittington Research Ethics Committee

Royal Free Hospital
Pond Street
London
NW3 2QG

Telephone: 020 7794 0552

Ms Marvelle Brown
Senior Lecturer (Haematology)
Thames Valley University
Paragon House
Boston Manor Road, Brentford
TW8 9GA

12 January 2010

Dear Ms Brown

Study Title:	**African and Caribbean communities experiences of cancer services in London**
REC reference number:	**09/H0721/57**
Protocol number:	**3**

Thank you for your letter of 05 January 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Decision: Provisional opinion

The Committee discussed the researcher's responses and agreed to give the study a provisional opinion.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

Further information or clarification required

1. In the section, 'What is the purpose of the study?' there should be a statement that you are also looking for good practices as well as areas that need improvements.
2. The Information Sheet does not follow the NRES guidelines which can be found on the website www.nres.npsa.nhs.uk > Guidance > Patient Information Sheets and Consent Forms. This will give you guidance on what to inform the participants on when using tape recordings and suggests that they should give consent to the use of tapes in the Consent Form.
3. It should be clear in the Information Sheet that the vouchers are a thank you for taking part in the study.
4. The Information Sheet should make it clear that participants may become upset during the interview and there should be an explanation what would be done if this was the case. It should also be mentioned that the participant could have someone with them during the interview if they preferred.

The REC nominated the Co-ordinator, Mrs K Clark, to be point of contact should further clarification be sought from the applicant upon receipt of the decision letter.

When submitting your response to the Committee, please send revised documentation where appropriate <u>underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates</u>.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 14 January 2010.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

| 09/H0721/57 | Please quote this number on all correspondence |