

**Help-seeking behaviours of Black Africans and African –
Caribbean People to diagnose HIV and AIDS**

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Abstract

With the advent of Highly Active Antiretroviral Therapy (HAART), people with the human immune deficiency virus (HIV) infection are increasingly enjoying longer and relatively healthy lives, particularly in developed countries. However, black Africans and African-Caribbean people in the United Kingdom and other developed countries are not yet enjoying the full benefits of HAART, essentially as a result of delayed diagnosis. Delayed diagnosis, in addition to affecting the health of infected individuals, also creates a community reservoir for the spread of the infection; thereby hampering prevention and control strategies by international and NHS guidelines. The delayed diagnosis may be grounded in individual, societal and health service factors that guide help-seeking behaviours of black African and African-Caribbean populations. This study set out to investigate the help-seeking behaviours to diagnose HIV and AIDS among UK based black African and African-Caribbean people, and to investigate the dynamics in those behaviours by place of origin (Africa vs. Caribbean) and by gender.

A qualitative methodological approach involving semi-structured interviews was used to explore help-seeking behaviours to diagnose HIV and AIDS among black Africans and African-Caribbean populations in the UK and compared by gender. Thirty (30) purposively selected individuals from patients attending two sexual health clinics in the city of London were interviewed. These included 16 black Africans and 14 African-Caribbean people, and 16 men and 14 women. The symbolic interactionist perspective, and the concepts of broken narratives/silences, biographical disruption and biographical abruption guided the study and interpretation of findings.

One main theme ‘Africanness’ and two sub-themes (“African way” and “African thing”) emerged from the findings. The “African way” embodies the risk factors involved in contracting or transmitting HIV and the “African thing” represents the HIV status itself. This is a cultural construction of HIV and AIDS within the acceptable context of participants which helped them to talk about HIV and AIDS without addressing it by the biomedical idiom. The notion of ‘Africanness’ provided a ‘marker’ for African identity. The “African thing” represented a new landscape for naming HIV without necessarily calling it by name and provided a comfortable platform for participants to seek help. The “African way” described the risk behaviours by participants that resulted in the “African thing”.

Three sociological concepts; ‘broken narratives or silences, biographical disruption and biographical abrupton were key issues in HIV and AIDS diagnosis at a late stage and have formed the basis for the development of a model of help-seeking for diagnosis by participants. Apparently, the main determinants of help-seeking for diagnosis of HIV and AIDS are dependent on cultural factors. Stigma is reinforced by the national health care system practices as well as health professionals themselves. This potentially increases the reluctance among black African and African-Caribbean populations to voluntarily test for HIV.

An HIV diagnosis is seemingly a challenging experience because of the impending uncertainties associated with it. Seeking help for diagnosis may even be more difficult because of the anticipated and unpleasant experiences along the path to diagnosis. This may guide the individual to consider other alternatives outside the biomedical pathway, potentially; the biomedical path becomes the least likely choice, especially with black African and African-Caribbean populations. An insufficient cultural understanding is likely to result in inadequate recognition of alternative medical practices, insufficient attention to

alternatives to biomedical health systems and potential distortion of the meaning of health messages linking them to practice.

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Abbreviations and Meaning

AHPN.....	African HIV Policy Network
AIDS.....	Acquired Immune Deficiency Syndrome
CAM.....	Complementary and Alternative Therapy
CAQDAS.....	computer assisted qualitative data analysis software
CDC.....	Centre for Disease Control
CD4.....	Cluster Designation 4
CDSC.....	Communicable Disease Surveillance Centre
DOH.....	Department of Health
GCP.....	Good Clinical Practice
GMC.....	General Medical Council
GP	General Practitioner
GUM.....	Genito – Urinary Medicine
HAART.....	Highly Active Antiretroviral Therapy
HIV.....	Human Immune - deficiency Virus
HPA.....	Health Protection Agency
IRAS.....	Integrated Research Application System
MDG.....	Millennium Development Goals
MND.....	Motor Neurone Disease
NHS.....	National Health Service
NMC.....	Nursing and Midwifery Council
REC.....	Research Ethics Committee
R&D.....	Research and Development
RNA.....	Ribonucleic Acid

SSA.....Site Specific Assessment
SSI.....Site Specific Information
STI.....Sexually Transmitted Infection
UK.....United Kingdom
UNAIDS.....Joint United Nations Programme on HIV/AIDS
UNICEF.....United Nations International Children's Emergency Fund
USA.....United States of America
WHO.....World Health Organisation
WHCCAM.....White House Commission on Complementary and Alternative
Medicine
WMA.....World Medical Association

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Chapter One

Introduction and Background

1.1 Introduction

It is documented that black Africans and African-Caribbean people in London are diagnosed with the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS) at relatively advanced stages of the disease compared with other populations such as the white population, despite the availability and accessibility of highly active antiretroviral therapy (HAART) (Del Amo et al 1998, Saul et al 2000, Barry et al 2002, Erwin et al 2002, Burns et al 2005, 2007, 2008). Although the availability and accessibility of HAARTS may create the impression that black Africans and African-Caribbean people should seek biomedical help, there is also the failure to remember that seeking biomedical healthcare may only be one of many options available to them given that their health beliefs may have been influenced by their cultural beliefs. The aim of this study therefore is to explore and improve the understanding of the help-seeking behaviours of black Africans and African-Caribbean people to diagnose HIV and AIDS, and to compare the help-seeking patterns among these two groups as well as investigating the potential differences by gender in their behaviours.

The ability of people to decide to respond to symptoms of illness by attending a health service for diagnosis may often be taken for granted. This may make help-seeking for diagnosis of illness to appear less of a problem than it actually may be. It may seem awkward to think that someone needs an ability to make a decision about seeking help despite

symptoms which may often be uncomfortable and disruptive to the individual's biography. This, however, may be true for some illnesses particularly those that may embody an element of stigmatisation such as HIV and AIDS as will be seen later. This research focuses on the help-seeking behaviours of black African and African-Caribbean people to diagnose HIV and AIDS.

This chapter, (Chapter One) provides a background on the issues of HIV and AIDS amongst black African and African-Caribbean people in the United Kingdom (UK). It also presents the rationale for carrying out the study, provides the aims and objectives of the study and concludes with summaries of each chapter in this study.

1.2 Background

In light of the increasing black African and African-Caribbean populations in the UK and the high prevalence of HIV and AIDS noted amongst them (Low et al 1996, De Cock 1997, Saul et al 2000, HPA 2007, 2008), the control of HIV and AIDS in these populations is a major challenge (Anderson and Doyal 2004, Owuor 2009) facing not only the UK but the world in general. This has further been jeopardized by limitations that black Africans and African-Caribbean populations have in seeking HIV and AIDS treatment (Erwin et al 2002, Ibrahim et al 2008). The increasing availability and accessibility of effective antiretroviral therapy provides a strong rationale for seeking help early for diagnosis in order to reduce morbidity and mortality associated with HIV infection (Saul et al 2000, Elford et al 2008). However, a reasonable proportion of people from African and Caribbean backgrounds living with HIV and AIDS in the UK are still diagnosed in healthcare settings with advanced stages of HIV infection (defined as either a CD4 count of <200 cells/mm³ or an AIDS defining illness at

HIV diagnosis, HPA 2008) and AIDS (O'Farrell et al 1995, Low et al 1996, Del Amo et al 1998, Saul et al 2000, Burns et al 2001, Barry et al 2002, Erwin et al 2002, Anderson and Doyal 2004, HPA 2007, Elford et al 2008).

The UK *National Strategy for Sexual Health and HIV (DOH 2001)* was published in 2001 with the following aims: 1) to reduce the transmission of HIV and sexually transmitted infections (STI); 2) to reduce the prevalence of undiagnosed HIV and STI; 3) to improve the health and social care for people living with HIV and 4) to reduce the stigma associated with HIV and STI (DOH 2001). Since then, the control of HIV infection, even though noticeable among the white population has not been significant among black ethnic minorities¹ (Anderson and Doyal 2004), especially black African and African-Caribbean groups (HPA 2007).

In addition, the UK White Paper: *The National Health Service (NHS) Plan (DOH 2000)* highlighted the need to address health inequalities and to narrow the gap between health needs and health services (DOH 2000), an issue that was echoed in the *Black Report* (Townsend and Davidson 1992). One of the objectives of the NHS plan was to tackle among different groups, the fundamental causes of health problems and discrimination ensuring that different health needs were recognised as this would be the starting point to tackle them.

The UK Public Health White Paper, '*Choosing Health: Making Healthy Choices Easier*' (DOH 2004) also had sexual health on its agenda and specified tackling HIV as one of its key

¹ Black ethnic minorities or black ethnic minority groups in this study are used as an umbrella term for black Africans and African-Caribbean people. Occasionally where African or Caribbean is used, they refer to black African or African-Caribbean.

objectives. It is clear that tackling HIV is challenging especially among black Africans and African-Caribbean people and these challenges will be discussed later in the findings. The paper emphasized the importance of securing better access to healthier choices for people in disadvantaged groups or areas in the UK. Lord Darzi, the then Parliamentary Under-Secretary at the department of Health, in his report, *High Quality Care for all: NHS Next Stage Review* (DOH 2008) highlighted sexual health as one of the 6 key areas that needed to be tackled. The current UK White Paper, '*Equity and Excellence; Liberating the NHS* (DOH 2010) has also highlighted the importance that the government places on public health by having as one of its objectives the improvement of public health and tackling health inequalities.

The UK Department of Health still faces the challenge of HIV and AIDS prevention in black African and black Caribbean populations (Anderson and Doyal 2004, Owuor 2009). Significantly, while black Africans made up only about 0.8% of the total UK population according to the 2001 census, they contributed 32% of the UK population of individuals living with HIV in 2002 (Barry et al 2002). The proportion of individuals with HIV infection diagnosed in the UK among black Africans increased from 24% (376 out of 1,598) in 1996 to 58% (3,323 out of 5,732) of all newly reported HIV infections in the country, and for which ethnicity was recorded in 2003 (Morris 2008, HPA 2009).

In all, it was estimated that about 53,000 adults in the UK were living with HIV and AIDS at the end of 2003, and that about 27% of them were undiagnosed. The estimated total population with HIV or AIDS was 6,100 for African men (with about 1/3rd being undiagnosed) and 10,100 for African women with about 14% undiagnosed (AIDSMAP 2004). In 2007, about 2,691 new HIV diagnoses were reported among black Africans, representing 40% of all new diagnoses in the UK but the number of new diagnoses among

Caribbean people remained lower (189), representing 3% of new diagnoses in 2007 (HPA 2008). In the same year, black Africans were reported to have the highest percentage of late diagnoses with 42% (1,104/2,691) of late diagnoses recorded among them and 27% (50/189) reported among Caribbean people. In 2008, 2,790 (38 %) of the new HIV diagnoses in the UK were among black Africans (HPA, 2009). In total, 23,288 black Africans received HIV care in the UK in 2009 (HPA 2010). There were also speculations that several thousand more Africans living in the UK [may be up to 11,000 individuals or more (HPA, 2005)] have undiagnosed HIV infection since HIV prevalence is many times higher among Africans in the UK than among the white majority.

Both in the UK and around the world, there is a general trend indicating that women are generally more likely to be infected by HIV than men. This is mirrored in prevalence statistics of HIV and AIDS infections in women in developing countries such as Cameroon (WHO/UNAIDS/UNICEF 2008). According to estimates from the United Nations Joint Programme on HIV and AIDS (UNAIDS 2002), there are more women living with HIV and AIDS than men. The UNAIDS data show that, by the end of 2002, almost 50% of the 38.6 million people living with HIV and AIDS at that time were women and in sub Saharan Africa, more than 55% of HIV positive adults in 2002 were women (Sacktor 2002) and the United Nations Joint Programme on HIV and AIDS (UNAIDS 2010) Report on the Global AIDS epidemic indicates that more than half of all people living with HIV and AIDS are women (UNAIDS 2010). According to the WHO/UNAIDS/UNICEF Report for 2008 (WHO/UNAIDS/UNICEF 2008), this imbalance persists despite efforts to overturn the existing burden of HIV and AIDS in highly affected populations. This imbalance has been attributed to many factors among which are biological, sexual and perceived social

constructed gender differences between men and women in roles and responsibilities which underpin behaviour, and access to resources and responsibilities (Matlin and Spence 2000).

1.3 HIV screening among black African and African-Caribbean

Populations

Screening is an important aspect of HIV and AIDS prevention and control in all populations. While the number of newly diagnosed HIV and AIDS infections is increasing steadily among the Caribbean population in the UK (Dougan et al 2004, Anderson et al 2008, 2009), this has long been the trend among African populations and such infections are thought to have been acquired both in the UK and abroad prior to migrating (Sinka et al 2003, Burns et al 2005, HPA 2008, UNAIDS 2008) with an increasing number becoming infected in the UK (Pebody 2009). Studies such as that by Fenton et al (2002) have shown that roughly two-thirds of Africans in the UK have never tested for HIV. It is also documented that this group of people are often diagnosed with HIV or AIDS at an advanced stage of disease and often during hospitalization for treatment of different illnesses (Erwin et al 2002). For instance, in 2007, about 42 per cent of black Africans diagnosed with HIV were diagnosed late (HPA, 2008). Besides the delay in seeking diagnosis, another challenge confronting the government is the control of spread and the minimization of stigma amongst these populations.

1.4 Study rationale

Many reasons justify why this study was deemed necessary. Firstly, it was part of the requirements for the doctorate programme in health research being undertaken. Secondly, in clinical practice an increasing number of the younger generation of black African and

African-Caribbean people with advanced HIV disease has been observed. This has been a cause for concern especially because of the availability of HAART and the ease of access to health services. This observation shifted my interest from peri-operative nursing care to the sexual health of black Africans and African-Caribbean people although I had no background experience in sexual health. My new found interest in the sexual health of black Africans and African-Caribbean people earned me an award (the Mary Seacole Leadership Award), thanks to which I was able to undertake a project on HIV awareness and prevention with black African and African-Caribbean youths in the community. This concern for the increasing numbers of late diagnoses of HIV among these populations is based on one of the principles of the National Health Service (NHS) since its creation in 1948 that the NHS is free to all at the point of use with provision of care based on need and not the ability to pay (*A National Health Service 1944*). Thirdly, some qualitative studies of help-seeking to diagnose HIV and AIDS among other black ethnic populations have been conducted in the United States of America (e.g. Kelly et al 1989, Prowden 2003, Bhattacharya 2004, Bogart and Thorburn 2006, Edwards 2006, Kraft et al 2007). Much has been written about HIV and AIDS in black Africans in the UK (e.g. Burns et al 2001, 2005, 2007, Barry et al 2002, Anderson and Doyal 2004) but very few of these studies address help-seeking patterns to test for HIV and AIDS among black Africans (e.g. Burns et al 2005). Moreover, in the UK such a field of inquiry has been dominated by quantitative studies with their main focus on stage of presentation (CD4 count) of HIV and AIDS and epidemiology and little focus on the social significance of illness on the sufferer (Smaje 1996).

No qualitative study was identified that addresses help-seeking patterns among black Africans and African-Caribbean people together and which explores how accounts of help-seeking patterns varied among black African and African-Caribbean groups. Furthermore, no

study was identified that compares the impact of gender on help-seeking among these two groups. There is therefore a necessity for exploratory work on help-seeking behaviours of black Africans and African-Caribbean people to diagnose HIV and AIDS and to ascertain any variations in accounts of help-seeking patterns among these two groups and among men and women in the UK.

In order to understand the help-seeking behaviours of black Africans and African-Caribbean people to diagnose HIV and AIDS, the study draws on the concepts of ‘broken narratives’ or ‘silences’ highlighted by Drakos (2008) in the context of cultural orientation, biographical disruption (Bury 1982) and biographical abruption (Locock et al 2009) described in Chapter Two and the symbolic interactionist perspective described in Chapter Three. Culture is defined as ‘a set of implicit and explicit guidelines that individuals inherit as members of a particular society, that tell them how to view the world, how to experience it emotionally and how to behave in it in relation to other people, to supernatural forces or Gods and to the natural environment’ (Helman (2007, p2).

Drakos (2008) described ‘broken narratives’ or ‘silences’ as the way people feel prevented from or do not feel at ease talking about their own or relatives’ illness status. Although each individual may have their own unique way of behaving when faced with symptoms of illness, cultural orientation may guide the way a group of people behave in such circumstances. However, in such circumstances slight differences may be expected in behaviour by gender, race and age.

Learning more about how black Africans and African-Caribbean people seek help to diagnose HIV and AIDS and understanding the variations in accounts of help-seeking among black Africans and African-Caribbean people, and among black African and African-

Caribbean men and women, is intended to provide valuable information to help develop culturally, psychologically and socially compelling primary health care programmes. These programmes may ameliorate access to timely diagnosis and treatment, and thus may reduce the prevalence of HIV infection and its complications among black Africans and African-Caribbean populations. The understanding from this research is also intended to help health care planners or policy makers to plan interventions based on the understanding of cultural influences on help-seeking patterns among these groups of people.

1.5 Research Questions

1. What are the views and experiences of black African and African-Caribbean people in relation to accessing health services?
2. How do black Africans and African-Caribbean people seek help to diagnose HIV and AIDS?
3. How do black Africans and African-Caribbean people vary in their help-seeking patterns to diagnose HIV and AIDS?
4. How do accounts of help-seeking to diagnose HIV and AIDS vary among men and women in these groups?
5. What other kinds of help (e.g. religion, complementary therapy) might black African and African-Caribbean people have sought before reaching health services?

1. 6 Aims and objectives

1.6.1 Aim

1. To investigate the help-seeking behaviours to diagnose HIV and AIDS among UK based black African and African-Caribbean people, and to investigate heterogeneity if any, in those behaviours by place of origin (Africa vs. African-Caribbean) and gender.

1.6.2 Objectives

In a group of black African and a group of African-Caribbean populations, both residing in UK:

1. To examine their views and experiences in accessing health services.
2. To determine how they seek help to diagnose HIV and AIDS in health services.
3. To explore the alternative approaches and places of help-seeking for HIV diagnosis.
4. To compare accounts of help-seeking among two groups overall and by gender.

This chapter, (Chapter One) has provided a background to this study and a justification for conducting the study. It has provided the aims and objectives of the study. The rest of the dissertation consists of six other chapters whose summaries conclude this chapter.

Chapter Two presents a review of literature on HIV and AIDS and help-seeking for diagnosing HIV and AIDS. The literature reviewed is organised in two sections. The first section of the chapter presents public health perspectives of HIV and AIDS and help-seeking among black African and African-Caribbean people. The second section of the chapter examines social science literature on HIV and AIDS and help-seeking among these groups of people.

Chapter Three describes the methodology that was adopted for this study. It justifies the approach and the method adopted to collect data for the study, and discusses the processes of obtaining ethical approval and of recruiting participants into the study. The process of negotiating access to potential participants is discussed. The chapter further outlines issues encountered in the field, in trying to secure space for interviewing participants. It highlights the field dangers inherent in researching sensitive areas and the eminent dangers that were missed during fieldwork. Lastly, the chapter discusses ‘identity’ problems that were encountered while conducting the study. The discussions in this chapter follow a reflexive approach. Strategies to maintain the trustworthiness of the methodology used for this study conclude the chapter.

The analysis is presented in three chapters (Chapter 4, 5 and 6). Chapter four, the first of the series, presents the key findings relating to participants’ perceptions of HIV and AIDS, through identifying themes using a thematic approach. The aim of the chapter is to highlight the study participants’ understanding of HIV and AIDS, and to show how their knowledge or lack of knowledge about HIV and AIDS may not only influence their coping strategies, but, also how it may affect their risk and health behaviour and consequently their ability to seek help for diagnosis. It also aims to highlight how this may influence the way participants lived and experienced their illness and consequently the decision to seek help. The chapter also compares knowledge about HIV and AIDS between black Africans and African-Caribbean people and between men and women.

Chapter Five, the second in the series of chapters on the analysis of key findings, examines ‘Africanness’ which is a term that embodies black African attitudes, and behaviours that appear to place them at risk of contracting or transmitting HIV and AIDS as described by

participants themselves. ‘Africanness’ has been portrayed in many contexts in the current study and even as HIV and AIDS. This chapter therefore, analyses the different contexts of ‘Africanness’ as used by participants from Africa and those from the Caribbean in this study. Such perspectives among black African and African-Caribbean participants are also compared.

Chapter six, the third in the series of chapters on analysis of key findings, analyses the pathways to help-seeking to diagnose HIV and AIDS. This chapter analyses triggers to help-seeking and discusses the various ways that participants in the study responded to symptoms. Some impediments to help-seeking such as lay perceptions of illness causation are analysed. It shows how these perceptions influence the pathways to help-seeking for diagnosing HIV and AIDS. Barriers to access to health services from the participants’ perspectives are presented and analysed. The impact of complementary and alternative therapy on the pathways to help-seeking is also presented and analysed. The chapter concludes with a comparison of perceived barriers to help seeking behaviour among the two groups and between genders.

Chapter 7 discusses the key findings from the study and shows how these influence help-seeking behaviours for diagnosing HIV and AIDS. It discusses the implications of key findings from the study and highlights and discusses some of the issues relating to HIV prevention and care among black African and African-Caribbean people in the UK. Most important here is the analysis of the main theme ‘Africanness’ and the two main sub themes: ‘African way’ and ‘African thing’. A model of help-seeking by these two groups is presented and the implications of findings for professional practice are presented. Help-seeking behaviours among the two groups and among men and women studied are compared. The

strengths, challenges and limitations of the study are discussed here. Some future research needs conclude the chapter.

Chapter Two

Literature review

2.1 Introduction

With the availability of HAART and the perceived ease of access to sexual health services, it is a major concern that many black Africans, are still being diagnosed with advanced stages of HIV infection compared to the white population (Del Amo et al 1998, Saul et al 2002, Barry et al 2002) and AIDS related illnesses (Erwin et al 2002, Burns et al 2005, HPA 2008, Ibrahim et al 2008). This chapter examines both public health and social science literatures (sociological, anthropological and psychological) relating to help-seeking to diagnose HIV and AIDS. It focuses on behaviour patterns that are likely to influence help-seeking to diagnose HIV and AIDS as well as cultural influences. Some social science literature (e.g. Awah 2006, Rhodes et al 2008) was also identified, that addressed the help-seeking behaviour of minority groups in the UK and in Africa with other chronic illnesses such as diabetes and epilepsy. The chapter is organised in two sections. Section one, addresses public health literature and section two social science literatures relating to help-seeking behaviours for diagnosis with HIV and AIDS.

2.2 Public Health Perspectives on HIV and AIDS

This section examines public health perspectives on HIV and AIDS. The literature identified examines factors associated with uptake and utilisation of HIV and AIDS services by black African and African-Caribbean people. It discusses the ethnic differences and variations in

stages of presentation with HIV and AIDS for diagnosis. The section begins with general information about HIV and AIDS.

2.2.1 General Information on HIV and AIDS

The human immunodeficiency virus (HIV) is a lentivirus, member of the retroviridae family (Weiss 1993, Douek et al 2009). Two major species of HIV viruses (namely HIV-1 and HIV-2) have been identified, with HIV-1 further comprising many groups and subtypes of viruses (Reeves and Doms 2002, Gilbert et al 2003). Human contamination with HIV leads to chronic, progressive infectious disease characterised by the destruction or impairment of the functions of the body's defence system, also known as immune system. Infection with HIV and the subsequent derangements of host immunity place affected patients at risk of secondary infections (opportunistic infections), malignancies and neurological disorders (Sacktor 2002, Douek et al 2009, Barasa 2011). HIV infection ultimately leads to the development of the Acquired Immune Deficiency Syndrome (AIDS), primarily characterized by opportunistic infections, cancer, and neurologic problems (Douek et al 2009).

HIV infection is diagnosed through biological proofs of the presence of the virus in the body. These include testing for the presence of antibodies (body defence proteins) raised against HIV or testing for the presence of parts of the virus like the ribonucleic acid (RNA). AIDS is diagnosed through indicators of the progression of HIV infection, including: clinical symptoms and opportunistic infections; biological markers of immune depression and cluster designation 4 (CD4) cell count in particular, or marker of intensive viral replication (HIV RNA level or viral load). Since 1982, about 30 years on from the discovery of AIDS, and 1985, about 27 years from the identification of the causative agent (HIV), multi-sectorial efforts have gradually converted HIV and AIDS from a potentially deadly disease into a

chronic disease, which may result in infected people surviving for several decades with the infection. A landmark achievement has been the advent of HAART, thanks to which, gaps in life expectancy between people with HIV and those without it have been narrowed substantially, particularly in developed countries (Anderson and Doyal 2004, Elford et al 2008). However, there is still no cure for HIV infection, implying that those contaminated with HIV will spend the rest of their lifespan with the virus in their body. Early identification of infected people, followed by initiation of HAART in those in need and encouraging adherence to prescribed medications are currently the main ways for preventing the devastating consequences of the disease in those with HIV infection. Similarly, there is at present no vaccine against HIV infection, making the prospect of a total eradication of the disease unlikely in the near future. Current efforts focus on preventing the transmission/acquisition of the infection by controlling the main known sources of contamination (Barasa 2011).

2.2.2 Public Health definitions of HIV and AIDS and classification

One of the very early attempts to define the disease came from the Centre for Disease Control (CDC) in the United States of America (USA). In this otherwise complex definition, the CDC conceptually defined AIDS as a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease (CDC 1982). To operationalize this definition, the CDC also identified a set of criteria to be combined at the individual level to determine if they were suffering from the disease or not (Box 1). The World Health Organisation (WHO) also presented a more simplified definition of the Acquired Immune Deficiency Syndrome (AIDS) as ‘an infectious disease caused by the HIV virus (WHO 1985). The evolving knowledge on the disease and the inappropriateness of the initial definition to some settings with high burden of the disease,

have attracted subsequent revisions of the CDC definition. These revisions conducted both by the CDC and the WHO initially aimed at identifying a definition that accommodated the lack of laboratory facilities by developing countries.

Across successive definitions, measurement of CD4 lymphocytes level has remained the landmark criteria for defining AIDS. Because CD4 counts may not be possible in some settings with high burden of the disease such as sub-Saharan Africa, the WHO (1987) devised a score of clinical symptoms and opportunistic infections to help detect the advanced stages of HIV and AIDS infection and start patients on treatment as appropriate in those settings. As such the ‘Bangui definition’ of African HIV and AIDS by WHO is more definitive of African HIV and AIDS (WHO 1985). The WHO defined African AIDS in terms of the duration of symptoms. According to them, AIDS is a definitive diagnosis when a patient has two of the following three symptoms: ‘prolonged fevers for a month or more, weight loss over 10 per cent, or prolonged diarrhoea,’ combined with any one of several minor symptoms such as chronically swollen lymph nodes, persistent cough for more than a month, persistent herpes, itching skin inflammation or several others (WHO 1985). As such, public health definitions of HIV and AIDS have been reviewed frequently by the WHO and CDC to embody any new emerging symptoms that characterise HIV and AIDS.

AIDS is a definitive diagnosis when a patient has two of the following three symptoms:

- prolonged fevers for a month or more,
- weight loss over 10 percent,
- or prolonged diarrhoea, combined with any one of several minor symptoms such as:
 - chronically swollen lymph nodes,
 - persistent cough for more than a month,
 - persistent herpes,
 - Itching skin inflammation or several others (CDC 1982).

Text Box1: CDC (1982) Definition of AIDS

2.2.3 Modes of Transmission of HIV

Three documented modes of transmission of HIV-1 are well known to date and include: the sexual, the percutaneous (through body fluids) and the perinatal (from mother to child) modes (Lifson 1988, Gershon et al 1990, Barasa 2011). However, there is some controversy from the public around the possibility of transmission of HIV-1 by other routes other than the well documented ones but there is insufficient evidence to support this (Gershon et al 1990). The possibility that breast milk may transmit HIV continues to be evaluated (Lifson 1988, Barasa 2011) although to date the belief is that HIV can be transmitted in breast milk. For this reason HIV infected mothers are advised not to breast feed. Additionally, the HIV virus has been found at low concentrations in the saliva, tears and urine of infected individuals. Although populations remain cautious with such secretions, there is little or no epidemiologic evidence of infections that have been transmitted by these secretions and the potential risk of transmission has remained insignificant (Lifson 1988).

The sexual route remains the most common mode of HIV transmission (Douek et al 2009). HIV infection occurring through blood products has also been found to be a common route of transmission with infections occurring as a result of unscreened or infected blood transfusion or through injecting drugs. This transmission route can therefore account for infections in intravenous drug users and people who require regular blood transfusion or other blood products such as haemophiliacs (Douek et al 2009). However this risk is greatly reduced with appropriate blood screening before transfusion. The transmission of the virus from mother to child can occur in either of three phases i.e., *in-utero* (during pregnancy), *intra-partum* (at childbirth), or via breast feeding (Coovadia 2004) although possible transmission via breast milk is still debated.

2.2.4 Stage of HIV and AIDS at diagnosis

With the current limitations in fully preventing and curing HIV infection and AIDS, early detection and treatment of those with the infection are currently the major approaches to both HIV and AIDS management. The goal of detecting and treating is however, variably met in various settings and across different population sub-groups within settings around the world including the UK.

Few studies indicate that a significant number of black Africans and African-Caribbean people are diagnosed with HIV at advanced stages unlike the white population. For instance Saul et al (2000) in a study conducted to ascertain ethnic differences and demographic variations in stages of presentation of HIV and AIDS at diagnosis in the UK, found that of 450 patients with newly diagnosed HIV from documentary analysis, 50% were classified as having a white background (white category not broken down) and 38% were black Africans. They found that 48% of the black Africans were diagnosed through a hospital department.

This finding is supported by subsequent findings from Erwin et al's (2002) study showing that a high percentage of black Africans in the UK were diagnosed with advanced stage of HIV disease. They also noted a higher CD4 count in patients classified as white, with black Africans 3.2 times more likely than patients with a white background, to present with a CD4 count $\leq 350/\text{mm}^3$. Further findings showed that 23% of patients presented with an initial AIDS diagnosis but this did not vary by ethnicity or risk factor. However, a potential limitation of this study is its basis on documentary evidence which gives no indication of how these groups of people sought help for HIV and AIDS diagnosis. It should be remembered that each culture has its own beliefs about health and illness and these beliefs define their help-seeking practices. Seeking help late for diagnosis later in the course of an illness maybe understood within this context.

Similar to Saul et al (2000), Boyd et al's (2005) retrospective review to establish the ethnic differences in stages of presentation of newly diagnosed HIV-1 infections in South London found significant variations in CD4 counts in the groups studied with the African group presenting with the lowest CD4 count compared with others. The sample comprised of 270 (54.7%) black Africans, 45 (9.1%) black Caribbean and 179 (36.2%) white people. They found that black Africans were more likely to present with AIDS diagnosis (21.3% and a lower CD4 count $< 223 \text{ cells/mm}^3$) compared to patients classified as white (9.9% and a CD4 count of 358 cells/ mm^3) and black Caribbean (17.9% with 294 cells/ mm^3). They also found that a majority of black Africans (58.4%) were tested for HIV as a result of suggestive symptoms or antenatal screening rather than because of perceived risk (40.5%) in contrast to the situation in white patients (24.1% versus 71.7% respectively) and black Caribbean people (34.5% versus 65.5% respectively). They found that most white patients were diagnosed in the genito-urinary medicine (GUM) clinics and black African and Caribbean patients on the

ward as in - patients. Their study supported earlier findings by Saul et al (2000), and Erwin et al (2002) that black Africans presented for diagnosis with advanced HIV illness. Their findings suggested low risk perception among black Africans as justification for late diagnosis.

Unlike the above studies that focused on stage of presentation at diagnosis of HIV disease, Fenton et al's study (2002) focused on demographic and behavioural factors associated with HIV testing among Africans. This was a cross-sectional survey (part of a larger community based participatory research initiative – the MAYISHA project) comprising 748 migrants from 5 sub-Saharan African countries (Congo, Kenya, Uganda, Zambia and Zimbabwe) residing in London. Their study associated testing for HIV with age and a history of previous sexually transmissible infection diagnosis among women, and nationality, education, employment, and self-perceived risk of acquiring HIV among men. The study concluded that HIV testing remained largely associated with an individual's STI history or self-perceived risk.

A similar cross-sectional community based survey (the MAYISHA 2) by Sadler et al (2007) in London, Luton and the West Midland on a sample of 1359 black Africans, found that 9.2% of participants had undiagnosed HIV infection. The study also found a significantly higher prevalence of HIV in men born in East Africa with a history of a previous STI diagnosis. A higher prevalence of HIV was also found in those who were recruited in bars and clubs and women born in East or Southern Africa who had had two new sexual partners in the past 12 months or who had a history of a previous diagnosis of an STI. The late presentation for diagnosis with HIV infection goes against the context at least in the UK where free access to screening services exists to promote early detection of infection and disease.

Similar studies of help-seeking for HIV have been conducted in other countries for example, a study by Bhattacharya (2004) of health care seeking for HIV and AIDS among South Asians in the USA explored other factors and suggested that immigration status, socioeconomic level and familial factors influenced help-seeking. He however emphasised the importance of understanding contextual factors that may affect help-seeking.

It is therefore of interest to explore the knowledge on the use of screening services for HIV by black Africans and African-Caribbean people in the UK and to ascertain whether they actually even perceive the need to get tested.

2.2.5 Perceptions of Risks and Help-seeking for HIV

Studies on the uptake of HIV testing among black Africans and African-Caribbean people in the UK have generated variable findings. Together, these studies suggest that uptake of HIV testing among black Africans and African-Caribbean people in the UK may be associated with many factors. Burns et al's (2005) study to describe the factors associated with HIV testing among heterosexual black Africans aged 16 – 44 years living in Great Britain found that more women (44%) than men (36.4%) studied, had previously had an HIV test which may suggest a potential impact of gender on help-seeking. HIV testing was also associated with social and risk factors such as being born abroad, having a new partner(s) from abroad in the past 5 years, and attending a GUM clinic among men; and educational attainment, perception of ‘not very much’ personal risk of HIV and attending a GUM clinic among women. They concluded that black Africans appeared to have relatively high rates of HIV testing reflecting some awareness of risk behaviours and potential exposure to HIV. This however seemed to contradict findings by the Communicable Disease Surveillance Centre

(CDSC 2001), Saul et al (2000) and Erwin et al (2002) which confirm that many black Africans are diagnosed at an advanced stage of HIV disease. However, it is not clear from Burns et al's (2005) study, at what stage of the disease black African people studied, tested for HIV and whether the increased rates of HIV testing noted by Burns in their study could have been related to their wives' antenatal screening.

Other studies also conducted in the UK to examine uptake of HIV and AIDS services such as that by Erwin et al (2002) with black African HIV positive people living in London, focused on the place and stage of diagnosis. Their study noted that 25% of black Africans were first diagnosed in a hospital ward. They also noted significant delays in seeking help for diagnosis of HIV and AIDS with this group of people despite suspicions of a possible positive HIV status, compared with patients with a white background. Other studies (Burns et al 2005, 2007) have made similar observations thus suggesting a potential lack of awareness among this group of people of their entitlement to care and availability of HIV and AIDS care services. For example, 20% of black Africans that participated in the study expressed concerns over entitlement to care and where to get an HIV test.

Studies have been conducted to identify issues affecting utilisation of HIV and AIDS health services in the UK from the perspective of non-service users. In such a study by Burns et al (2007) conducted among black Africans in the UK, from the perspective of key informants, institutional barriers to care were identified including the lack of cultural understanding, lack of open access or community clinics, failure to integrate care with support organisations and the inability of many General Practitioners (GP) to address HIV related issues. The authors suggested that community involvement should include input to ensure a better cultural understanding within the health care system, normalisation of the HIV testing process and a

clear message on the effectiveness of therapy may improve access to HIV and AIDS care by this group.

2.2.6 Utilisation of opportunities for HIV Testing

Opportunities for early diagnosis of HIV other than voluntary testing exist, but some studies have shown that such opportunities are often missed at medical consultations. For example Burns et al (2008) study to identify opportunities for earlier HIV diagnosis in black Africans with newly diagnosed HIV infections in fifteen HIV treatment centres across London, found that despite the large number of patients (263) that attended medical consultations, many of them (131) were later diagnosed with advanced HIV infection. Their study highlighted the failure of clinicians to use such opportunities effectively for preventive and diagnostic purposes among this population. Their study also called on clinicians to be more proactive in addressing HIV due to low appreciation of personal risk and lack of perceived ill health within this community.

Although this study highlighted missed opportunities for diagnosis, it did not highlight the reasons for accessing health services at such times. Unless routine testing for HIV at all medical encounters becomes policy, it might not be appropriate to test for HIV at every medical encounter unrelated to HIV and AIDS, given that the subject of HIV and AIDS is a delicate area and such an approach may keep people away from seeking help even for other illnesses other than HIV and AIDS. My study joins those summarised above to explore those factors involved in help-seeking that cause black Africans and black African-Caribbean people in this case to present late for diagnosis.

2.3 Social Science Perspectives of HIV and AIDS

Before examining HIV and AIDS from social science perspectives, it is worthwhile mentioning some key works on chronic illness that demonstrate how chronic illness affects individuals' biographies. Such works identified concepts such as 'biographical disruption' (Bury 1982), 'narrative reconstruction' (Williams 1984), 'loss of self' (Charmaz 1983), 'biographical abrupton' (Locock et al 2009), 'biographical reinforcement' (Caricabaru and Pierret 1995), 'broken narratives' (Hyden 2008) and 'silences' (Drakos 2008). These studies demonstrated the impact of chronic illness on everyday life and showed how this can affect help-seeking with illnesses. Given that black Africans and African-Caribbean people in particular are diagnosed at advanced stages of HIV and AIDS disease (Saul et al 2000, Erwin et al 2002, Burns et al 2005, 2008), it is worthwhile understanding how these pioneering works may directly or indirectly guide an understanding of help-seeking for diagnosis with HIV and AIDS.

The following paragraph reviews the impact of symptoms on help-seeking. As Siegel et al (1999) put it; people may be suffering with chronic illnesses and experiencing changes or disruptions in biography without necessarily accessing health services for diagnosis. Alternatively, people suffering from HIV and AIDS for example black Africans and African-Caribbean populations may turn to other ways of coping or seeking help for healing from sources that are not recognised by the western biomedical system. For example, turning to alternative to medical systems such as spiritual approaches (Ridge et al 2008) or doing ancestral consultations and performing sacrifices (Hillenbrand 2006) and thus may delay seeking help from the recognised western medical system. Ridge's et al (2008) study highlighted the notion of prayer as a form of therapy that is sought by black Africans and

African-Caribbean populations living with HIV and AIDS in Africa, the Caribbean and in the UK and emphasised the importance to them, of the different meanings attached to these practices which may impact on help-seeking behaviour.

The following section discusses the influence of symptoms on help-seeking with illness. Some models and theories of help-seeking are discussed. The section begins with a brief analysis of the concept of help-seeking.

2.3.1 The Concept of ‘Help-seeking’

‘Help-seeking’ is a concept that is used to explore and understand patients’ delay or prompt action to seek care in relation to health problems. It is used interchangeably with ‘health-seeking’ and is described as part of both illness and health behaviour (Cornally and McCarthy 2011). While Gibbs and Lurie (2007) described ‘help-seeking behaviour’ as the actions of individuals or groups in search of something to affect their performance in their social roles at the optimal level, Cornally and McCarthy (2011, p 282) have summed up all these terms and have defined ‘help-seeking behaviour’ as:

‘a problem focused, planned behaviour involving interpersonal interaction with a selected health care professional’.

This definition implies that individuals are able to react to noticeable changes in their personal functioning in a given environment as well as within themselves that may require attention. Such attention is the action taken by the individual/group to change the difference e.g. seeking a diagnosis or acquiring treatment (Gibbs and Lurie 2007). For behaviour to be

recognised as ‘help-seeking’, the individual must acknowledge a change within himself which requires a decision to be made and requires that either action or no action be taken in an attempt to positively affect the change and reinstate equilibrium (Gibbs and Lurie 2007).

Seeking help requires a decision making process and Scott and Walter (2010) describe this as the process of symptoms perception, interpretation and appraisal to give them meaning before a decision is made. What is important here which they consider as an essential step is the ability and motivation of the individual to enforce the decision by visiting a health care professional or facility. Various definitions of help-seeking show that it is a process (e.g. O’Mahoney and Hegarty 2009, Scott and Walter 2010), that starts as a response to a problem which unfortunately the individual is unable to solve using his own means alone and therefore requires interaction with someone (Bamberger 2009). The Nursing Outcome Classification (2010) definition differs slightly in that it sees help-seeking behaviour as personal action to promote optimum wellness, recovery and rehabilitation. Although the elements of this definition show that help-seeking is a response to a problem, there is greater indication that help-seeking can occur in the absence of a problem, for instance, when individuals engage in health promotion and disease prevention activities not as a response to symptoms.

2.3.2 Models of help-seeking

Many models of help-seeking (Rosenstock 1966, Mechanic 1968, Zola 1973, Snow’s 1974, Leininger 1991) have attempted to explain factors that influence help-seeking behaviour but only few have provided a holistic view of such factors. For instance, Zola (1973) and Mechanic’s (1968) models suggested social and psychological factors that caused people to seek help with illness. Zola (1973) identified 5 factors, which he called triggers, which

included interpersonal crisis, interference of illness with personal or social relationships, sanctioning by others, interference with physical activities and temporalizing.

Mechanic (1968) in a similar manner identified 10 factors from which he noted that determinants of illness behaviour were self-defined or defined by other people. He pointed out that decisions to seek help were based on the visibility of symptoms and the ability to recognise them, perception of the symptoms as dangerous, availability of information and knowledge about the symptoms and cultural assumptions. He suggested that people would seek help if there was any form of disruption to work, family and other social activities by the symptoms, and if these symptoms were frequent and persistent, and if the individual was able to tolerate and interpret the symptoms. Mechanic (1968) also suggested other factors such as psychological and financial costs, expressed in money, time and effort loss and costs related to social distance, stigma and humiliation. While both models provide a wide variety of factors that influence the decisions to seek help they both focus mainly on social and psychological factors although Mechanic (1968) recognised financial costs.

Unlike Mechanic and Zola, Snow's (1974) model which takes on an ethno-medical approach laid emphasis on the notion of folk beliefs as a key element in the decision to seek help with illness. Snow (1974) saw the world as a hostile and dangerous place, where individuals were liable to attacks from external sources which rendered them helpless without internal resources to fight such attacks. Her model suggested that malice is embedded in pessimism about the nature of human relations and the conviction that most people will do ill when it was of interest to them. Snow's (1974) model however focused mainly on folk beliefs and a punitive God.

Other models that have attempted to explain help-seeking include anthropological models such as that of Kleinman (1980). Kleinman takes a more holistic view of factors that are likely to cause people to seek help by integrating psychological, sociological and cultural elements. According to his model, determinants of health care seeking behaviour included the type and severity of symptoms, course of sickness, type of sick role, specific sickness labels and their associated causes, evaluation of specific therapeutic interventions and social factors such as, age, sex, family role, occupation and educational level of the patient, the family's socioeconomic status, ethnic background, orientation to western or traditional values and past experiences with health care, urban or rural setting, the proximity to particular treatment resources, the nature of the patient's social networks and lay referral systems. Kleinman's model is therefore more holistic.

Psychological models, for example, the Health Belief Model (Rosenstock 1966) focused mainly on psychological factors and is therefore limiting in that psychological factors alone may not be enough to trigger help-seeking. The Health Belief Model attempted to explain and predict human behaviour in relation to disease prevention and health promotion practices. The model depicted internal and external motivators influencing health behaviour and includes the following constructs: perceived barriers to undertaking the behaviour, perceived susceptibility to an illness, cues to action, perceived benefits of the behaviour, perceived severity of the illness and self-efficacy. These constructs can be used to identify factors that act as motivators and those that act as barriers to seeking care. The Health Belief Model therefore suggests that the decision to seek help involves the interaction of an individual's beliefs, values and culture as well as the individual's perceptions about the personal costs and benefits of seeking care and treatment.

There are other models which have specifically been attributed to black people e.g. Leininger's (1991) theory of Culture, Care, Diversity and Universality. Leininger's (1991) theory aimed to discover and explain diverse and universal culturally based factors influencing the health, well-being, illness or death of individuals or groups. Her theory aimed to provide care measures that are in harmony with an individual or group's cultural beliefs, practices, and values. Her theory emphasised that care is the essence of nursing and has meaning within cultural contexts and pointed out that many variations are required in patient care to support compliance, healing and wellness. Her theory explained, interpreted and predicted culture, care and knowledge and life ways. It also explored a combination of dimensions that provided an understanding of actions and thoughts. Such included; education, economics, religion, philosophy, family/kinship and politics which are considered as critical social dimensions influencing the cultural development of individuals and of values, thoughts and behaviours. She suggested that these dimensions influenced the perceived ability of black people in particular to seek care which impacts health behaviour. However, this theory, unlike many of the models already discussed above provides a more holistic perspective to address factors that can trigger help-seeking for diagnosis of illness.

2.3.3 Gender and Help-seeking

Gender has been described by WHO (2008) as the socially constructed set of attitudes, beliefs, behaviours and attributes or structures that are considered by society as appropriate for men and women. Possible differences in help-seeking with illness between men and women have been the focus of some debates, with some studies showing that gender affects help-seeking, with women seeking help more than men do (Green and Pope 1999, Boros et al 2000, Bertakis et al 2000). Noone and Stephens (2008) suggested that seeking medical help earlier in the course of an illness is critical for recovery. Advantages of seeking help earlier in

the course of an illness include among others, a reduced cost to the health service, improved health outcomes and greater chances of survival (Taplin et al 1995). Some studies (e.g. White 2001, DOH 2002) in the UK have highlighted the reluctance of men to seek health services for diagnosis and care and their infrequency in seeing the doctor. In addition to the unlikelihood of men to visit the doctor when they are ill, they are also unlikely to report symptoms of disease (DOH 2002, Moller-Leimkuhler 2002). Addis and Mahalik (2003) attributed these differences in help-seeking to the categorisation of men and women into two homogenous and mutually exclusive biological groups. However, Noone and Stephens (2008) highlighted that social theorists and an analysis of the social construction of gender on the contrary, have attributed these differences in help-seeking behaviour between men and women not to biology but to social influences.

In a similar way to Bohan (1993) who argues that appropriate masculine behaviours are constructed in direct opposition to those constructed as feminine behaviour, Courtenay (2000) and Saltonstall (1993) argued that health care practices are gendered with men relatively unconcerned about their health and well-being. Addis and Mahalik (2003) and Courtenay (2000) asserted that such practice is related to men's perceptions that they are physically and emotionally stronger than women and visiting the doctor would imply vulnerability and weakness. Further justification for failure of men to seek help has also been highlighted by Sanden et al (2000). They suggested that the perception by men that seeking help was not an obvious solution to the health problem they faced and the ability of physical problems to cure themselves was justification for men's failure to seek help. Therefore, seeking expert care was generally regarded as strange behaviour for men.

Another study by Richardson and Rabiee (2001) using semi-structured interviews with a group of young men aged 15-19 concluded that help-seeking behaviour was dictated by social norms which required that a health problem be both physically and sufficiently severe to justify needing help. They found that the reluctance to seek help was also associated with the idea that GPs were not a good choice for confiding about illness because of the discomfort associated with communication issues and feelings of vulnerability. Furthermore, Gascoigne and Whitear (1999) found the feelings of embarrassment, the unwillingness to appear foolish and the determination to normalise symptoms the main causes of reluctance to seek help in their study of people diagnosed with testicular cancer. Gascoigne and Whitear (1999, p.67) therefore suggested that such behaviour was ‘a reflection of powerful internalised gender notions of masculinity and masculine identity’.

Although it is documented (Hunt et al 1999) that women tend to seek medical attention more than men, there have equally been contradictions with some studies (e.g. Feeney et al 1998, Macintyre et al 1999, Emslie et al 1999, Fernandez et al 1999, Gijsbers van Wijk et al 1999) suggesting that there are no gender differences in help-seeking with illness. They argued that the case for differences in help-seeking between men and women may only exist because women’s tendency to see the doctor peaks in their reproductive years. However, other studies have highlighted inconsistencies in help-seeking behaviour of men and women for example, Galdas et al (2005) in a review of men and help-seeking behaviour concluded that studies comparing men and women were inadequate in explaining the process involved in help-seeking behaviour. Similarly, Hunt et al (2011) in their study to compare the help-seeking behaviour of men and women suffering from headache and back pain found no significant differences in their help-seeking behaviours.

2.3.4 Ethnicity and Help-seeking

2.3.4.1 Perspectives on Ethnicity

The relationship between ethnicity and health has been identified as a relatively under-researched area from a sociological perspective (Smaje 1996) although there has been more recent work by e.g. Ahmad and Bradby (2007) and others. In the past, most studies of ethnicity and health have been based on both clinical and epidemiological perspectives with focus on the patterns of disease among different populations and little or no attention paid to the social significance of illness to these populations (Smaje 1996, Bhopal et al 1999, Nazroo 2001, Bhopal 2007). Before examining the perspective on ethnicity it is worthwhile defining and analysing the concept of ethnicity and race particularly as these two concepts seem to be misunderstood and are frequently used interchangeably. The following section therefore defines and analyses the concepts of ethnicity and race.

2.3.4.2 Ethnicity and Race

The use and meaning of the terms ethnicity and race by researchers has not been clearly understood (Lee 2009). While ethnicity refers to people with a shared ancestry and shared culture (Mason 1995, Bhopal 2007), the term ‘race’ describes a group of people with some shared biological or genetic traits (Giddens 1991). Both terms have been used interchangeably although there is a conceptual distinction between them (Agyemang et al 2005) and Sheldon and Parker (1994) highlighted the difficulty in using these two concepts. Therefore measuring health and health related behaviour across racial and ethnic groups may pose real problems if these terms are not clearly understood.

The term ‘race’ refers to the separation of people into groups based on their physical characteristics resulting from genetic ancestry such as skin colour (Bhopal 2007). Senior (1994) in more simple terms described race in reference to biological homogeneity based on phenotypical features. It is also well documented that genetic differences tend to occur within rather than between continental groups (Agyemang et al 2005) and this is explained by the fact that the genes responsible for physical characteristics that underpin race are few and not related to behaviour or disease (Bhopal 1997). This has resulted in the scientific value of race being highly debated because of this genetic variation (Sheldon 1992). However race remains an important political and psychosocial concept.

Similarly, ethnicity is also a controversial concept with many meanings attached to it (Manly 2006). Despite these multiple meanings, it still remains very useful in medical research. Its definition as stated below includes characteristics such as shared origin, shared culture and distinctive traditions that are maintained between generations giving them a sense of identity (Bhopal 1997). Ethnicity has been described as a multifaceted concept that refers to the group to which people belong or to a common ancestry as a result of certain shared characteristics. These characteristics may also be linked to geographical origins and to people who may sometimes share a common language, religion and social customs (Mason 1995, Bhopal 2007, Ahmad and Bradby 2008). It may also be seen as the way people define themselves in relation to others. Similarly, Ahmad (1992) described ethnicity in two ways: firstly as a mode of identity by which people group themselves and have a sense of belongingness. He emphasised on the distinction of an ‘us’ from a ‘them’ and secondly he defined ethnicity as a principle of social structuring. However, these still remain problematic as the ways ethnic groups have been defined require further clarification (Sheldon and Parker 1992, Senior and Bhopal 1994, McKenzie and Crowcroft 1996). For instance, all black Africans in particular

seem to be defined as having a common ethnicity. Although they may be of the same race there may be some minor differences especially social differences among them. There may even be more fundamental differences when comparing black Africans with African-Caribbean people. The term ‘African’ or ‘Caribbean’ may not convey sufficient information to consider these two groups as homogenous from a scientific perspective (Hutchinson and Mckenzie 1995).

Race and ethnicity therefore define a minority group, because the group shares common characteristics (physical or cultural) which force it to occupy a low status in society in relation to other groups. Ahmad and Bradby (2007) suggested that the focus on distinguishing traits such as skin colour and hair texture has resulted in the exaggeration of differences at the expense of similarities between people. This implies that race and ethnicity are social and cultural constructions and in order to understand them, culture and social interaction rather than biology have to be understood. These terms are of particular importance in this study because of the diversity in belief systems in relation to health and healing (Vaughn et al 2009) among different cultural groups and these two groups studied are not different in this respect. Such beliefs include feelings about healthcare providers themselves and seeking westernised healthcare and the use of traditional and indigenous healthcare practices and approaches (Vaughn et al 2009). Because ethnicity embodies cultural, behavioural and environmental factors that all have the potential to increase risk of disease, it remains an important concept especially for epidemiologists and clinicians (Manly 2006).

Race and ethnicity are cultural creations for physical distinction between different groups of people. But the concepts of race and ethnicity have evolved from being a mere physical device for distinction, through political and psychological devices to determine human

interactions into another realm of cultural discourse – health. These two concepts have holistic attributes needed to be considered for all sociocultural analysis. Some authors (e.g. Bagley 1995, Fullilove 1998) advocate that racial and ethnic classification be abandoned as a health measure variable because the way in which these two constructs are used may not only increase the potential for stigmatisation but may also reinforce stereotyping. This is likely to render attempts to measure health and health related behaviours challenging.

The use of other variables to measure health and health related behaviour other than race and ethnicity have been advocated by some researchers (e.g. Manly 2006). Some of them have suggested the use of variables such as acculturation, socio-economic status, educational level, and culture as they are considered to have independent influences on health behaviour and health outcomes. There is, however, potential to misunderstand and misuse racial/ethnic classifications and this potential therefore has to be addressed by exploring factors that underlie the differences. Emphasizing the effects of cultural experience on behaviour, attitudes, and other health outcomes is likely to downplay the importance of racial classifications and to highlight the distinctiveness and depth of culture (Berry 1976, Padilla 1980, Moyerman and Forman 1992). Racial classification reveals nothing about cultural, socioeconomic, educational or racial experiences and these are likely to influence health behaviour. Before continuing to review ethnicity and race, brief definitions of the terms black, black African, African, and Afro-Caribbean are examined in the next section.

2.3.4.3 Definitions of black, black African, African, Afro-Caribbean

Although these terms have been used throughout this work, there have been some debates about the appropriateness of their use in health research. Agyemang et al (2005) pointed out

that their use may in some circumstances be inaccurate and offensive and therefore should be minimised. In this piece of work their use provides a description of the populations studied and provides a basis for comparing the help-seeking behaviours of the two groups. Bhopal (1997) points out that ethnic population of African descent are often not well defined. In support of this, Kaplan and Benneth (2003) suggested that, addressing the heterogeneous Africans as ‘black’ renders comparability of these populations between places and times more challenging and reinforce the notion that being black is one of the causes of health disparity.

The diversity within these groups especially in Europe and the USA have been highlighted especially in terms of beliefs, behaviours, risk factors and disease experience (William 1997, Oppenheimer 2001). Similar to data on diversity among African descent populations² in the US, diversity among these populations in the UK has also been highlighted by Balarajan (1991), Low et al (2001) and others. This point is illuminated by, Cappucio et al (1998) who have given an example using rates of smoking. They state that rates of smoking among Afro-Caribbean people have been shown to be considerably higher than in West Africans and this difference is lost when the two groups are considered as a homogeneous group. Additionally, some studies (e.g. Elam et al 2004) on these two groups living in England have highlighted their differences in religion, diet, migration experience, education, language and health behaviours.

Grouping of African descent populations as black or black Africans, for example, is likely to obscure the huge heterogeneity within these groups. This is likely to weaken the value of

² African descent populations in this text refer to people with African descent and include black Africans, African Americans, and African-Caribbean or Afro-Caribbean populations.

ethnic categorisation as a means of providing culturally appropriate health care and in understanding the causes of ethnic differences in disease. These broad definitions however are unlikely to fit in well with self-definition of ethnicity. ‘Black’ has been used to describe heterogeneous populations but it is unrelated to ethnicity. Below are definitions of black, black African, African and Afro/African-Caribbean.

The term *black* is a culturally constructed and socially recognised term used in this work to describe black Africans and African-Caribbean people. Generally used, this term usually refers to all non-white populations. It does not however, have any relation with ethnicity. Agyemang et al (2005) specify that its use refers to people with sub-Saharan African ancestral origins with black or brown complexion. They warn that the term should be used cautiously as it may simply refer to all non-white minority populations. Additionally, Comstock et al (2004) note that its use to denote African ancestry is deeply rooted in epidemiological and public health language, although the term *black* has a psychosocial and political significance. However, some authors (e.g. Senior and Bhopal 1994, Mckenzie and Crowcroft 1996) have highlighted the unhelpfulness of the term *black* in epidemiology and public health. Senior and Bhopal (1994) highlighted that not only does this term cover a wide range of ethnic and cultural backgrounds, it may also be potentially offensive and unreliable as it may not only mask epidemiology and public health heterogeneity of cultures among diverse African populations but it may also reinforce stereotypes.

The term *African* in the context of this study describes a native of the African continent born in Africa. Used in the context of scientific writing on race and ethnicity it usually refers to a person with African ancestral origin who self identifies or is identified by others as African (Agyemang et al 2005). The term *African* without qualification defines a population solely

on the basis of a common continental and ancestral origin and forms the preferred prefix for more specific categories with origins from the African continent such as African-Caribbean and African Americans (Agyemang et al 2005). They caution against the use of the term ‘African’ on its own and recommend its use as a prefix.

The term *black African* is used to describe people and their offspring who have African ancestral origins and who migrated directly from sub-Saharan Africa. Although used in epidemiological studies, it remains a very broad term and does not relate to ethnicity. Like the term African, Agyemang et al (2005) caution against its use.

The term *Afro-Caribbean* also understood as African-Caribbean refers to people and their offspring with African ancestral origins who as a result of migration from sub-Saharan Africa settled in the Caribbean Islands. Karlsen (2001) noted the inconsistent use of this term in the UK with some researchers using it to refer to black people of Caribbean descent and others to refer to people of West African descent (Haines 1987, Chaturvedi 1993). Such inconsistencies are likely to bring confusion especially in epidemiological studies. African-Caribbean people have cultural values which are different from other African populations in terms of language diet, customs, beliefs and migration history (Agyemang et al 2005). The use of the term *African-Caribbean* has also been challenged as this refers to people from a multitude of islands (Agyemang et al 2005). Although there are major similarities among black Africans there are also variations among black African populations from Africa.

Similarly, similarities and variations are expected among the African-Caribbean groups. The name African-Caribbean alone is not sufficient to pinpoint what part of the Caribbean the individuals are from or the diversity in their cultures. Therefore, examining these two groups

together as homogeneous may result in differences among each of the groups and between the two groups being ignored. This aspect is important in this study especially as participants were from many different countries both in the Caribbean and in Africa and differences in behaviours and attitudes would be expected. However, considering black Africans as a homogeneous group and African-Caribbean people as another homogeneous group in this has been based on broad cultural similarities among each of the groups.

Anthropologists perceive ethnic distinctions as a classifying device (Smaje 1996) whereby differences between people can be identified. Cohen (1985) has conceptualised ethnicity as a symbolic representation by which particular communities are able to provide themselves a social identity, and argues that the essence of such an identity is to provide a simplified and complete milieu around which the diversity of attitudes, behaviours and orientations can be reconciled. Although a community or group of people (for example black Africans and African-Caribbean people) may be internally different, they are likely to be perceived externally as homogeneous (Cohen 1985). This is likely to be the case because of their phenotype and this has the potential to result in stereotyping. This may also apply to the way black Africans and African-Caribbean people view themselves influenced by the way they are seen by western countries; as a homogeneous ethnic minority group, as an indicator of disadvantage as Ahmad and Bradby (2007) put it.

Although there may be no internal homogeneity among black Africans and African-Caribbean populations in terms of culture, this homogeneity may be noticed among African-Caribbean people or among black Africans in broad characteristics or cultural manifestations such as the way of dressing, traditional marriages, funerals and cultural responses to illness. The following paragraph offers a possible explanation to this.

Although Africa is a big continent with many different countries which have clearly defined geographical boundaries, major cultural practices tend to be similar within and across these boundaries especially south of the Sahara (Shah 2010). Prior to colonisation, Africa was made of few nations with many ethnic groups, fewer languages and minor cultural differences. Africa before colonisation could be described as one big village with almost ‘invisible’ cultural and geographical boundaries with few kingdoms (Shah 2010). African historical research indicates that pre-colonial African societies before the establishment of formal colonial control were unchanging.

Other research (Dowden 2008) into African history highlights the problem of border design during colonization which did not take into account cultural, geographical and ethnic boundaries. Europeans agreed that ethnic groups could freely move across colonial borders (Asiwaju 1985). This meant that citizens of one country could find themselves in more than two different countries taking along their culture to their new territory. Western, Sahelian and Southern African countries are good examples. The concept of ethnicity seems to be stronger than that of a nation state as people relate more with their kin in another country separated by colonial boundaries than with closer ethnic groups located within the same country. Moreover the treaty for the formation of African Union in 1964 signed by almost all African countries explicitly mentioned that nations would allow their citizens moving across the border. This to some extent meant that cultural boundaries (Mahoso 2010) became more blurred. Border artificiality also implied that heterogeneous ethnic groups were forced to be part of the same usually large country.

Africans existed within a reality of multiple, overlapping and alternative collective identities (Comaroff 1987, Taras and Ganguly 2002, Berry 2002). Other evidence suggests that the

notion of the individual person with a unique and bounded identity of western modernity did not exist until introduced under colonial rule (Clapham 1985, Shillington 1989). This meant that few or none of these new territories could lay claims to a cultural identity that was uniquely theirs. This also applies to issues of health and illness where there are always overlapping explanations and interdependence of the individual with the community.

Many ethnic groups are perceived as being more likely to suffer from different illnesses (Hutchinson and McKenzie 1995, Vaughn et al 2009) for example Asians have been associated with cardiovascular diseases (Bhopal 2007) and black Africans with HIV and AIDS (Shilts 1987). Black Africans for example have as a consequent come to identify themselves with HIV and AIDS. Some of the likely consequences of such perceptions include stereotyping and prejudice which are linked to disadvantage (Ahmad and Bradby 2007). This could be understood in terms of the labelling theory which has contributed to the development of the model of help-seeking described in the analysis chapter.

Labelling theory is concerned with how the self-identity and behaviour of individuals may be determined or influenced by the terms used to describe or classify them. It suggests that people obtain labels from how others view their tendencies or behaviours and Frank Tannenbaum (1938) has highlighted that such perceptions may cause the individual to adopt the label as part of their identity, i.e., the greater the attention placed on this label, the more likely the person is to identify himself/herself as the label. Labelling theory was developed to describe the subsequent behaviour of criminals but subsequently, it has been developed and applied to a much wider set of activities since its initial development. Labelling theory argues that formal societal reaction to crime can be the precursor to the development of a criminal career (Becker 1963) that is, the labelled person is increasingly likely to become more

involved in crime. Tannenbaum describes this as ‘the dramatization of evil’. This may be relevant to the current study in that black Africans have been increasingly associated with HIV and AIDS to the extent that they see HIV and AIDS as part of their identity and therefore they have labelled it ‘African thing’.

2.3.5 Influence of HIV Symptoms on Help-seeking

Many illnesses are preceded by symptoms which are often subjective in nature and can properly be appraised from the reports of the sufferer. The experience of symptoms appears to play an important part in the decision to seek help and this is based on the meaning attributed to the symptom by the sufferer (Armstrong 2003). To understand the influence of symptoms on help-seeking, few definitions of symptoms are presented in this paragraph. Lenz et al (1997) defined symptoms simply as:

“Perceived indicators of change in normal functioning as experienced by patients” (p.3).

Rhodes and Watson (1987) provided a more detailed definition of symptoms. They defined symptoms as a subjective phenomenon which is often regarded by those experiencing it as an indication of a condition departing from normal function, sensation or appearance or as perceived indicators of change in normal functioning. The experience of symptoms may be influenced by physiological, psychological and situational factors (Rhodes and Watson (1987). Symptoms may be regarded as the defining elements of illness (Siegel et al 1999). This maybe so because many illnesses are preceded by symptoms which may either be externally visible or reported by the patient.

Even though every culture may have their own ideas about the manifestation of illness, Cassell (1976) suggested that each of these cultures use ‘the symptom’ as the primary defining element of illness experience because ‘the symptom’ offers insights into the physiological and psychological aspects of the patient’s body. Vaughn et al (2009) suggested that different cultures have different disease theories which have attribution concepts that enable the explanation of disease causation. As such, non-western ideologies attribute disease causation to other factors such as intrusion of the body by spirits, social taboos or to witchcraft (Low 1985, Chipfakacha 1994, Madge 1998, Mulatu 2000) and some of these illnesses may not have external manifestations. These ideologies are likely to have implications for help-seeking behaviour which will be discussed later in the chapter.

Therefore, in non-traditional health care systems, while symptoms may be understood from a biomedical perspective, they also are believed to be manifestations of the intrusion of the body by the supernatural (Low 1985, Chipfakacha 1994, Madge 1998, Mulatu 2000). The interpretation of ‘the symptom’ is culturally constructed, and the cultural interpretation of the symptom plays a crucial role in the decision to seek biomedical help and consequently diagnosis and treatment of the illness (Low 1985, Helman 2007). Research on individuals at risk for HIV and AIDS infection suggests that the presence of symptoms often played a central role in the decision to seek HIV testing and medical care (Siegel et al 1999). Siegel’s study demonstrated that this decision to a large extent depended on the interpretation of symptoms and the meaning given to them by the patient. It can be argued that this behaviour is related to people’s lay beliefs that illness must include symptoms and to the reluctance of the patient to accept an illness identity especially that of a stigmatising illness. Although symptoms may be recognized by the sufferer as indications of disease, medical opinion and treatment are not always immediately sought by those suffering the symptoms (Scambler

1991). However, seeking medical opinion is only one of the many options available to individuals when they experience symptoms.

2.3.6 Chronic Illness and Help-Seeking

Studies (e.g. Bury 1982, Williams 1984, Charmaz 1983, Caricabaru and Pierret 1995, Hyden 2008, Drakos 2008 and Locock et al 2009) highlighted the impact of chronic illness on the individual's biography. HIV and AIDS have been conceptualised as chronic illness as many people with HIV and AIDS tend to live longer with their illness. Although this is the case, HIV infected people live and experience their illness differently. The following section draws on literature on the experience of chronic illness to help an understanding of the experience of people living with HIV and AIDS and its impact on help-seeking and their biography in general.

The concept of 'biographical disruption' (Bury 1982) portrays chronic illness as a disruptive event which affected life right from onset throughout the sufferer's biography. Bury (1982) emphasised the meaning and significance of the disruption to the sufferer and highlighted that chronic illness involves:

'a recognition of the worlds of pain and suffering, and the possibility even of death which are normally only seen as distant possibilities or the plight of others' (1982, 169).

He concluded that lay perceptions of symptoms and the decision to seek help do not necessarily coincide with those held by health professionals. He emphasised that the age at onset of chronic illness is important and made disclosure to significant others and outsiders problematic.

Another attempt to explain the experience of chronic illness beyond biographical disruption is highlighted by Williams (1984). His work looked at people with already established rheumatoid arthritis to understand their experience of illness beyond Bury's (Bury 1982) biographical disruption, i.e., the long term effects of chronic illness on self-concept. From his work he conceived the notion of 'narrative reconstruction' which described how people tried to adapt after the disruptions caused by onset of chronic illness.

More recent sociological studies have conceptualised chronic and terminal illness as 'biographical abrupton'. While these studies draw from Bury's (1982) concept of 'biographical disruption' they go further to highlight the experiences of chronic illness that may be terminal. For instance, Locock et al's (2009) study of people living with Motor Neurone Disease (MND) explored how they constructed their accounts of life with MND. In addition to the biographical disruption imposed by the illness, they identified participants' perceptions of their diagnosis as a 'death sentence' with the resulting belief that life was over. From their study, they also found that some of the participants tried to make sense of what was left of their lives by maintaining as much normality and control as possible, despite the debilitating effects of the illness, as well as finding new meaning of life and identity.

Other sociological studies (e.g. Carricabaru and Pierret 1995) further highlighted the impact of the onset of chronic illness such as HIV on lives that already had disrupted biographies. From their study, Carricabaru and Pierret (1995) highlighted that chronic illness also touched lives that were already suffering from other illnesses (or that already had disrupted biographies) whereby the patients had already reassessed these biographies and mobilised resources to cope with the disruptions as was the case with the haemophiliacs in this study. They suggested that the gay group in their study which was asymptomatic would eventually

come down with a disease although it was difficult to predict exactly when that would happen and until such a time they had to manage ‘an apparently healthy life in conditions of uncertainty’. Carricabaru and Pierret (1995) described this as a ‘sense of continuity’ as the participants tried to reinforce their identities based on their previous disrupted biographies either as haemophiliacs or as homosexuals which existed before their HIV diagnosis.

Charmaz (1983) developed the concept of ‘loss of self’ to describe the way chronic illness is experienced when she carried out a qualitative study of chronically ill persons with varied chronic conditions. She described this ‘loss of self’ as a ‘fundamental form of suffering’ in chronic illness. She highlighted that chronically ill people lived restricted lives, and noted that they were increasingly socially isolated, suffer discreditation (Goffman 1963) and sometimes ended up being a burden to others. From her study she concluded that chronically ill people saw their former self-images being destroyed by illness without being replaced by valued ones. Also, a sense of ‘loss of self’ might be evident in the ‘body unboundedness’ described by Lawton (1998) that sometimes characterised severe forms of some chronic and terminal illnesses for example AIDS that has progressed to a terminal stage.

Hyden and Brockmeier (2008) have attempted to show how people experience illness and how they try to make sense of life with illness. According to them people try to make sense of their illness and manage to cope through what they conceive as ‘illness narratives’. Through these narratives some chronically ill people share stories of their suffering with family and friends, and sometimes with health professionals as an attempt to find help and to give meaning to their experiences. Hyden and Brockmeier (2008) pointed out that some of these stories although told by people, who have no speech impairment, can often be described as ‘undecided, fragmented, broken and narrated by voices struggling to find words towards

meaning and communication'.

While narratives may be a way of giving meaning to experiences of illness and making sense of the new life with an illness (Hyden and Brockmeier 2008), Drakos (2008) highlighted 'silences' as another dimension of living the illness experience. Drawing from his study 'to understand what it is like to live as a next of kin to a person with HIV and AIDS in Sweden and Greece', Drakos (2008) highlighted the concept of 'silences' otherwise termed 'broken narratives' as a way of giving meaning to the experience of a chronic illness such as HIV and AIDS. 'Broken narratives' in voices that 'can be heard' (Drakos 2008) can be seen as a fundamental form of suffering in long term illness as well as a way of coping with illness. He described 'broken narratives' or 'silences' as the way people feel prevented from talking about their own or relative's illness status. According to him, narratives and silences shape the condition for what it is like to live with HIV and AIDS. Simmel (1906) called this 'secrecy' and described silences as a cultural practice in everyday life by which groups regulate their communication with the world. Goffman (1959) had also highlighted secrecy as a way of coping in which he noted that life is like a 'theatrical performance' whereby individuals present a public self and a private self; the public self being what people portray to the public and a private self being what they keep to themselves.

Drakos (2008) further described silences and narratives in two other dimensions; i.e., as embodied practices, justifying that narratives are the body and that through 'narratives' or 'silences' about HIV, people expose or conceal the state of their own bodies; and as a cultural practice which is important in understanding the significance of cultural differences for what it is like to live with or be related to an HIV or AIDS patient. Although 'silences' about HIV may be to avoid the stigmatisation linked to it, Drakos (2008) concluded that silences, could

be seen both as an indicator of suffering and as a means of avoiding suffering. Broken narratives or silences may therefore impact negatively on help-seeking in that when people feel prevented to talk about their illness they may suffer in silence without seeking help to diagnose their condition. The concepts of silences/broken narratives, biographical disruption and biographical abruptness therefore provide a conceptual basis for this study.

The next section explores cultural beliefs about health and illness and discusses how these beliefs influence people's decisions about help-seeking as well as the different pathways that they take to seek help with symptoms.

2.3.7 Cultural Beliefs about Illness Causation

Some authors (e.g. Helman 2001, 2007, Awah 2006) have noted that cultural beliefs and interpretations of illness causation and the meanings ascribed to these beliefs are important determinants of decisions about illness and consequently decisions about help-seeking. Helman (2007) has highlighted the influence of culture on many aspects of life including attitudes to illness and these may have implications for health and health care. Before presenting the influence of culture on illness, the following paragraph defines and analyses the concept of culture.

2.3.8 Culture

From an anthropological perspective, culture is defined as a system of shared beliefs, values, customs, and behaviours, that members of society use to cope with their world and with one another, and these are transmitted from generation to generation through learning (Kleinman

and Good 1985, Langdon and Wiik 2010). Helman (2007 p2) summed up the definition of culture as:

'a set of implicit and explicit guidelines that individuals inherit as members of a particular society, that tell them how to view the world, how to experience it emotionally and how to behave in it in relation to other people, to supernatural forces or Gods and to the natural environment'

Helman (2007) further described culture as an inherited 'lens' through which the individual perceives and understands the world that he inhabits and learns how to live within it. Taylor (2007) suggested that culture is observable in the form of personal behaviour and could be abstracted from individuals' actions and attributed to the social groups to which they belong. Culture in its broadest sense can be described as the totality of a person's learned experiences which is socially transmitted or acquired through social learning. It may be seen as the essential core which consists of traditional ideas especially their attached values (Helman 2007). Human beings are passive creatures and do whatever their culture tells them to do. Certain aspects of a culture may be learned consciously and others subconsciously.

Cultural beliefs about health and illness throughout Africa do not seem to have fully embraced biomedical causes (viral, bacterial, and traumatic) of illness but they also tend to attribute illness to factors such as superstition, ancestral and cultural causes (Chipfakacha 1994, Madge 1998, Mulati 2000, Helman 2001, Awah 2006, Awah and Phillimore 2008). Every society develops cultural theories which set parameters that determine causes of illness and consequently indigenous input in diagnosis and treatment. Kleinman (1980) called these

‘explanatory models’. These cultural beliefs or theories influence the way people perceive illness and its causes and these affect the way diagnosis and treatments are eventually sought.

Although Bojuwoye (2005) suggested that health in the African context is described as a state of equilibrium between the different levels of beings, ranging from God, the family, the ancestors, the environment to the community, he also emphasised that such a state of equilibrium is destabilised when there is a break in any of the components. As such an indigenous African perspective of illness can be described as complex and multifaceted, and incorporates religion, biology, spirituality and socio-ecological influences (de Graft 2005, Hillenbrand 2006, Awah and Phillimore 2008). For instance it is believed that some illnesses may arise from the failure to satisfy ancestors by performing rituals at required times for example during funeral celebrations of a deceased family member and this is communicated by the ancestors through illness (Awah and Phillimore 2008).

Generally, Africans classify the causes of illness in much the same way and LeBeau (2008) described this as the ‘African paradigm’ of classifying illness. However, there is no evidence to suggest that non-Africans do not perceive illness to have other causes outside biomedical causes (Monckton 1997, Kottak 2008, Vaughn et al 2009) but generally explanations for illness in western countries are rarely understood by a greater number of lay people in religious terms. A likely explanation is that while the western world relies on a naturalistic explanation (which assumes that illness is due to impersonal mechanistic causes in nature that can be understood and cured by applying the scientific methods) of illness (Gerber et al 2007), Africans rely on a personalistic tradition (which assumes that illness is due to the acts and wishes of other people or supernatural beings and forces) (Agleton 1990, Chipfakacha 1994, Hopwood 1997, Madge 1998, Mulati 2000). However, Eisenberg et al (1998) have

highlighted that the western world is becoming more interested in alternative healing practices such as acupuncture, homeopathy, herbal medicine and spiritual healing but this is done as adjunct to main therapy which is biomedically centred.

The medical model appears to have great influence on lay perceptions of health, with modern cultures adopting such perceptions making it difficult to focus on folk beliefs about illness. The influence of the medical model however is unlikely to change the perceptions of some racial minorities like black Africans who seem to ‘move with their culture’ (Gyekye 1997, Awah et al 2009) and tend to have embedded folk beliefs about health and illness. Ridge et al (2008) found that black Africans living with HIV and AIDS in the UK held on strongly to prayer for coping and as a way of healing. Black African-Caribbean people appear to have similar practices. The reasons, justifying why people rely on prayer when ill are varied and include the request for help from higher power in form of spiritual healing and seeking guidance from this power (Walton and Sullivan 2004, de Graft 2005, Awah and Phillimore 2008). Indigenous illness causes are therefore rooted in ideas and myths about sources and origins of illness and these are seen as manifestations of misfortunes in human experience.

In a nutshell, traditional people perceive disease and illness as reminders to the living to accord spiritual powers the respect they deserve (Geshiere 1995, Hillenbrand 2006, Awah and Phillimore 2008). As such, victims of such illnesses seek diagnosis and treatment from those believed to have supernatural powers, such as, traditional healers because of the lay belief that supernaturally caused illnesses are best managed by traditional healers (de Graft 2005, Awah 2006, Awah and Phillimore 2008). In this light, spiritually caused illnesses are also believed to be cured spiritually through a system of therapy supported by shared beliefs and myths about the causes of illness (Kirby 1993). Adhering to such beliefs may influence

help-seeking to a large extent. An understanding of these beliefs is therefore important in understanding help-seeking behaviours of black Africans and African-Caribbean populations. Help-seeking pathways are therefore determined largely by the perceived aetiology of the illness (Awah and Phillimore 2008), the subjective interpretation and the meanings attributed to symptoms (Castillo 1997, Siegel et al 1999, Ayorinde 2003).

2.3.9 Response to symptoms in the black African and African-Caribbean contexts

There are likely some variations in the response to symptoms of illness in western and non-western cultures. For instance, the response to symptoms appears to be quicker in western cultures than non-western cultures. This may probably be so because of the straight forward and limited pathways followed by patients to the health care system in western cultures (naturalistic approach) and probably because response to illness is an individual responsibility (Gyekye 1997, Vaughn et al 2009). This is recognised as a more complex issue in the African context (Awah and Phillimore 2008, Awah et al 2009). Explanations to this are linked to reactions to illness which sometimes require negotiations with social networks regarding the causes of illness and symptoms before the next steps to take towards help-seeking are decided.

Although black Africans seek the help of traditional healers, biomedicine is not completely undermined (de Graft 2005, Awah et al 2009). This may complicate the pathways to seeking help as both western and traditional systems may sometimes be sought simultaneously (Hillenbrand 2006) with the hopes that multiple treatment options will increase the probability of addressing all the causes of the disease or illness (Wandibba 1995, Kawango

1995, Awah and Phillimore 2008, Awah et al 2009). Similarly, in African-Caribbean countries, seeking help is not straight forward as other forms of therapy may be attempted before the biomedical scenery is eventually reached.

Some illnesses especially those that people think cannot be cured such as HIV and AIDS are often associated with witchcraft (Pool 1994, Awah and Phillimore 2008) and people revert to such explanations in terms of witchcraft when symptoms do not disappear. It should also be understood that patients even when they seek western healthcare bring their own worldviews, expectations, norms and taboos and these may pose significant challenges if they are not acknowledged or recognised by the healthcare provider. Although this approach may seem problematic, it reflects the cultural interpretations of distress and the need to tackle the health problem holistically.

Western notions of disease causation which are based on the biomedical model appear to be limiting and do not seem to sufficiently recognise the subjective nature of illness as well as cultural influences on illness causation. Despite these limitations, western notions of disease causation have considered indigenous ideologies as unscientific (Pool 1994, Helman 2007). It can be recognised that cultural factors often dictate the severity of symptoms, therefore influencing the treatment a patient may receive (Hahn 1995). People may also seek others (lay consultations) within their culture in regards to the management of their illness, and in doing so, ‘they also seek legitimisation for the symptoms they manifest before seeking the help of a practitioner’ (Low 1985: 191).

In conclusion, symptoms are an indication of illness but the sick individual’s cultural orientation has a part to play on how these symptoms are responded to both in western and non-western cultures (Kirby 1993, Helman 2007). This response in the black African and

African-Caribbean contexts is also determined by the perceived causes of illness (Awah and Phillimore 2008). In western cultures the biomedical health care system takes priority when people have symptoms, but indigenous black Africans in similar circumstances give priority to non-biomedical systems if symptoms of the illness are deemed to be spiritually caused (de Graft 2005, Awah and Phillimore 2008). The way people perceive health is therefore an important factor in determining how they seek help with illness. The following section discusses lay perceptions of health and their impact on help-seeking.

2.3.10 Lay Perceptions of Health

Social science studies show that lay beliefs about health are complex, diverse and sophisticated. Stacey (1988) advised that health professionals should always consider lay concepts about health when dealing with patients pointing out that such concepts are more than common sense. Prior (2003) argues that, although people may have lay knowledge, this may not be enough for understanding the technical complexities of disease, disease causation and clinical procedures. Although the WHO has given a clear and concise definition of health as “a state of complete physical, mental and social well-being of an individual, and not just the absence of disease or infirmity” (WHO 1948), lay people ascribe different meanings to health. This to a large extent is shaped by factors such as social class, socioeconomic factor, cultural factors, educational level, ethnic groups and religion.

To be healthy means different things to different people. Howlett et al (1992) noted from Blaxter's (1990) data that while Asians described health in functional terms, African-Caribbean people described health in terms of energy and physical strength and were more likely to have fatalistic views of illness causation, e.g. attributing illness to bad luck. Black Africans have constructed the meaning of health from a cultural perspective. Health to them

is viewed as being psychologically, physically and spiritually fit and in cosmic equilibrium (Kawango 1995). These dimensions are included in this definition because human factors are also believed to be part of disease causation to an extent that indigenous people believe that HIV and AIDS can be caused by human beings through spiritual means.

Other social science research into lay perceptions of health, indicate that perceptions of health by lay people are generally based on their functional, moral and emotional dimensions and are influenced by lifestyle, environment, social status and culture. For instance, Blaxter (1982, 1990), Williams (1984), Cornwell (1984), Herzlich (1973) amongst others have illustrated these lay perceptions of health by different groups of people. For example, Herzlich (1973) drawing from her study with middle class French respondents, showed that health is a function of an individual's lifestyle which may result in stress and nervous tension. Her study showed that lay people have clear ideas about the relationship between health and illness. While Herzlich (1973) provided a framework for understanding the relationship between an individual's lifestyle and health, Blaxter (1990) drawing from a large national study of lifestyle and health in the UK provided variations in the perceptions of health across different social groups. From her study Blaxter (1990) highlighted the notion of health as 'the absence of disease or health despite disease especially among the working class groups. Her study noted lay perceptions of health in dimensions which are applied to different areas of life and lifestyles (Blaxter 2004). For instance, lay people define health negatively as the absence of illness similar to Herzlich (1973), functionally as the ability to cope with every day's activities, or positively as fitness and well-being (Blaxter 1990). Both studies (Herzlich's and Blaxter's) are similar in that participants' perceptions of health are influenced by the medical model.

Other lay perspectives of health, highlight a moral element (Williams 1984, Cornwell 1984). Such studies, highlighting the moral dimension of health, pointed out that health reflected the maintenance of a healthy lifestyle, the response to illness and the ability to deal with its aftermaths especially illness that can potentially devalue one's identity. It is possible that this dimension may cause people not to respond to illness and Williams (1984) pointed out that it is common for a healthy status to be declared despite the accommodation of an illness by the body.

However, no evidence was identified to suggest that black Africans and African-Caribbean people define health in a unique way different from other races. In a similar manner to people in western cultures, where the medical model predominates, the definition of health centres on the absence of illness, the ability to function in daily roles and the ability to maintain a moral well-being. Taking into consideration the different views held by lay people about what health means; there is need to understand how people assess and make sense of their health and how they decide to seek help when they recognise that they are ill. The different dimensions by which health is conceptualised and understood by lay people are likely to influence the way they manage health, prevent illness or seek help with symptoms.

2.3.11 Lay Perception of HIV and AIDS Risk

Since the emergence of the HIV and AIDS epidemic, social researchers have attempted to highlight behavioural factors that compromise the control of the epidemic in different populations including black Africans and African-Caribbean people in UK and elsewhere. Studies into the use of condoms as an HIV infection control strategy suggested that black Africans have negative attitudes towards condom use (Taylor 1990, Sobo 1995, Kusanthan and Suzuki 1999, Sachingongu 2001, Trigg 2001, Fenton et al 2002). Nevertheless, the need to reduce the barriers to taking up HIV tests given the relatively low perceived risk in black

Africans (Fenton et al 2002) remains a vital control measure. However, the association between perception of risk of HIV infection and sexual behaviour remains poorly understood (Ward et al 2004), although perception of risk is considered to be the first stage towards behavioural change from risk-taking to safer behaviour (Akwara et al 2003).

There is growing consensus that the risk of contracting HIV and AIDS is shaped by socio-economic and political circumstances and is profoundly linked to poverty (Ward et al 2004). . It is worth noting that recognising HIV as a political issue and its attribution to some marginalised groups is likely to skew the risk perceptions involved in its transmission. The general belief that the risk of acquiring HIV is only in Africans and gay people is likely to result in greater exposure as there is the potential for people to not consider the risks involved in risky sexual behaviour with people other than Africans and gay people.

Few studies (e.g. Burns et al 2005, 2008) that explore risk perceptions of HIV and AIDS among black Africans and African-Caribbean people have been carried out in western countries. Most studies that explore risk perception of HIV and AIDS infection among black Africans in particular have been conducted in Africa. This is understandable given the significantly high rates and prevalence of HIV infections in Africa. One of such studies by Akwara et al (2003) in Kenya explored the perception of risk of HIV and AIDS and sexual behaviour between men and women. This study found a strong positive association between perceived risks of HIV and AIDS and risky sexual behaviour for both men and women. The study found that, while men reported having multiple sexual partners women reported having casual partners. Justifications for low perception of risks ranged from having fewer sexual partners to using condoms. Although some of the participants linked their moderate risk perception to their partners multiple sexual relations they could not do anything about it

which is explained by gender inequalities in Africa that place women in a subordinate position (Reid 1999). Furthermore, while Lowndes et al (2008) have shown that full knowledge about HIV and AIDS is lower in women than in men in Africa, Dunkle et al (2004) highlighted the lack of bargaining power among women during sexual encounters which place them at risk.

A similar study by Meeker and Klein (2002) on young people in Cameroon explored further into condom use as a response to risk awareness. Their study found a positive correlation between risk perception and condom use for males with casual partners, but no significant correlation for men with regular partners. For both men with regular and casual partners, the use of condoms was higher at the start of the relationship but dropped as the relationship progressed. This study suggested lower risk perception in long standing relationships.

Cultural meanings associated with lifestyle have also influenced the perception of HIV risk. This was the finding from Wight's (1999) study of 58 men aged 19 years old from Glasgow. Wight found that their perception of HIV risk was shaped by cultural meanings associated with their lifestyles and friendship groups related to their types of occupations as well as the stage of their partnership career. From Wight's work, lay people's perceptions of risk is informed by their scepticism about scientific knowledge and objectivity. This study demonstrated the complexities in risk perception among people in general. While risk is often thought of as a characteristic of a particular group of people, the case of HIV contradicts this belief as anyone can be at risk.

It can therefore be concluded that there is poor perception of HIV risk among all age groups. Although some people are aware that HIV and AIDS exist, is incurable and can be contracted through unprotected sex, the perception is that only 'other people' will contract it. In addition

to this, people in long term relationships perceive a low level of risk, so may not find it necessary to protect themselves against any potential infections. A low risk perception may imply that people do not consider it necessary to seek help for HIV testing both voluntarily or when they have symptoms.

Some people when ill fail to attend biomedical health services to seek diagnosis but sought other forms of therapy. The following paragraph discusses the impact of complementary and alternative therapy on help-seeking highlighting the use of other therapy as a help-seeking option. It presents the use of complementary and alternative therapies which include traditional/ethno medical practices, massage, acupuncture, prayer, food and many others but only traditional medicine will be discussed in more detail.

2.3.12 The Role of Complementary and alternative therapy

Although the effectiveness of complementary and alternative medicine (CAM) has been widely debated, its use in western countries is becoming widespread in recent years (Eisenberg et al 1998, Joos et al 2008) and has especially been recognised in the treatment of chronic conditions such as cancer. Reports have suggested that a high proportion of people living with HIV and AIDS use CAM. Despite this increase, there are variations in its use in different countries. Before examining its use and significance, it is worthwhile understanding what is meant by CAM. While Bratman (1997) defined alternative medicine as any practice that claims to heal but does not fall within the conventional medical practice, Dawkins (2003) defined alternative medicine as a set of practices that either cannot be tested, refuse to be tested or consistently fail tests. He pointed out that there is nothing like alternative medicine and emphasized that there is medicine that works and medicine that does not work. He suggested that techniques that have been proven to be effective through clinical trials become

known as medicine and no longer as alternative medicine. While Ernst (1995) described techniques used in conjunction with conventional mainstream techniques as complementary medicine, Barnes et al (2004) described them as alternative approaches.

CAM has been defined by the WHO as ‘a broad set of healthcare practices that are not part of that country’s tradition and are integrated into the dominant healthcare system’ (WHO 2002). Acharya et al (2008) highlighted the diversity of the methodologies of alternative medicine methods and suggested that such diverse methods may include traditional medicine, folk knowledge and cultural beliefs. While this may be used as adjunct to mainstream conventional medicine in developed countries, it is recognised as a treatment option in developing countries as a result of restricted access to essential medicines due to lack of resources. In Africa, traditional medicine is very popular and is used for up to 80% of primary healthcare, as over one-third of the population lack access to essential medicines (WHO 2003).

The White House Commission on Complementary and Alternative Medicine (WHCCAM) (2002) noted that the strength of alternative medicines lies on its ability to individualise treatment, while at the same time treating the person holistically. Alternative medicine while promoting self-care and self-healing also recognizes the spiritual nature of each individual. Its main disadvantage is that practice is not based on scientific evidence and therefore the effectiveness is questionable based on the lack of evidence (Kopelman 2004). Those having experienced or perceived success with one alternative therapy for a minor ailment may be convinced of its efficacy and persuaded to extrapolate that success to some other alternative therapy for a more serious possibly life-threatening illness (Navarro and Senior 2006). That has been the case with some of the participants studied as will be seen later in Chapter 6.

Other studies (e.g. Foote-Ardah 2003) have noted that some people use complementary therapy with biomedicine and others use it alone in the management of HIV and AIDS. The need for complementary therapy varies among HIV and AIDS patients who use it with different meanings attached to its use. For instance, Pawluch et al (2000) found varied meanings attached to complementary therapy use from their qualitative study with HIV infected people using complementary therapy. They found that the use as a health maintenance strategy, as a healing strategy, as an alternative to western medicine, as a way of mitigating side effects of drug therapies, as a strategy for maximising quality of life, as a coping strategy and a form of political resistance were some of the meanings attributed to complementary therapy. They also found that these beliefs were linked to social characteristics such as sexuality, ethno-cultural backgrounds and gender and to beliefs about health and illness, values and experiences. Foote-Ardah's (2003) study with HIV patients found that, in addition to managing symptoms, medications and emotions, CAM was also used to evaluate disease progression, gain freedom from medical regimen and manage AIDS stigma.

Another study by Thorpe (2009) in Australia, examined how people living with HIV discussed their use of complementary medicine and their attitudes towards complementary medicine practitioners and biomedical doctors several years after the introduction of HAART for HIV. They found that 73% of the respondents used complementary therapy. Their analysis suggested that diagnosis with a chronic illness continues to be a disruptive experience and therefore the need to adopt new perspectives and approaches for health and illness.

The use of CAM is not limited to HIV and AIDS alone. Parallel studies to demonstrate the effectiveness of CAM with biomedicine in other chronic illness has been demonstrated by Rhodes et al (2008) in their study of the use of biomedicine, CAM and ethno-medicine for the treatment of epilepsy among people of South Asian origin in the UK. Their study demonstrated the effectiveness of lay referral systems in help-seeking and the notion of support in chronic illness that has disrupted lives. Another similar study has been carried out by Awah (2006) on diabetic patients in Cameroon. His study demonstrated the importance of ethno medicine among indigenous people suffering with diabetes.

Traditional medicine is a form of alternative therapy that is beginning to receive much attention, with the WHO soliciting its recognition as a legitimate form of therapy. It is described as the art of healing illness (Feierman 1985, Kirby 1993, Awah 2006). The WHO (2002) noted that the numerous elements that constitute traditional medicine and its characteristics make it difficult to be defined clearly and concisely. The WHO however, described traditional medicine as the diverse health practices, approaches, knowledge and beliefs that incorporate plants, animals, mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being as well as to prevent, diagnose or treat illness (WHO 2002). Some countries, for instance, Cameroon and South Africa, have formed national traditional medicine associations which work together with biomedical health professionals in their respective countries and are regulated by the ministries of public health. It is clear that traditional healers play an influential role in the lives of black African people but more importantly they have the potential to serve as crucial components of a comprehensive health care strategy (Kirby 1993, Awah 2006, Awah and Phillimore 2008). Although no record of cases of HIV and AIDS patients that have been successfully cured with traditional medicine, have been identified, it however seems to play a

vital part in slowing the progress of the illness or prolonging the lives of black Africans. Traditional medicine can be considered as the first point of help for many black Africans before they eventually reach the biomedical health care services when their illness does not subside (Awah 2006).

2.3.13 HIV and AIDS Stigma

HIV and AIDS are perceived as highly stigmatising conditions in many societies including the UK. This perception is likely to affect the response to symptoms of the disease especially in relation to disclosure and seeking help. To understand how stigma impacts on help-seeking for diagnosis and subsequent care, the concept of ‘stigma’ is briefly described. Goffman (1963) defined stigma as “an attribute that is deeply discrediting within a particular social interaction” (Goffman 1963:3). He described stigma as a form of deviance and identified two forms of stigma: Felt-stigma which describes victims feelings about being HIV positive and the reactions they fear from others; and enacted stigma which describes the actual experience of stigma among people infected with HIV.

Carlisle (2001) noted that despite the greater understanding of the transmission and effects of HIV and AIDS and the availability of information on it, prejudice still exists. She suggested that uncertainty around the cure for HIV remains a strong influence on the way HIV and AIDS impacts psychologically on those who have been infected. The understanding that HIV is incurable suggests that society views it differently from the way it perceives other illnesses. This may be understandable because the fear which can be engendered by disease for which there is no cure or which may result in death can create irrational emotional and behavioural reactions (Sontag 1991).

The tendency is to view HIV and AIDS as something which happens to other people and particularly to people who are different either in their behaviour or sexual orientation (Carlisle 2001) or their colour. Such perceptions elicit a stigmatising response in society which affects the way people seek care. People who are not infected with HIV and AIDS perceive it as death and this challenge elicits a distancing stigmatising response (Marris 1996). This affects help-seeking when they become infected with the HIV virus. Moreover, the general perception is that HIV is contracted sexually which probably carries a negative connotation. People infected with HIV may therefore conceal their diagnosis or maintain silences about their HIV status to conceal their positive status and to keep secret their mode of contracting the illness (Carlisle 2001).

Concealing an HIV status can have a significant effect on the decision to seek appropriate healthcare (Carlisle 2001) which may result in people being diagnosed at a later stage of illness as highlighted by Saul et al (2000), Erwin et al (2002) and Burns et al (2005, 2008). However, the ability to conceal an HIV diagnosis is compromised when the plethora of symptoms makes it impossible for the victim to conceal the true nature of the disease (Alonzo and Reynolds 1995). This may result in dishonesty about diagnosis as a strategy to conceal the true nature of the illness as will be seen later. Such individuals are likely to avoid seeking help and as a consequence are also likely to be diagnosed at an advanced stage. Stigmatisation has also been reported among healthcare professionals (Herek 1999, Infante et al 2006). This is likely to have a profound impact on the decision by patients to seek help for diagnosis with HIV and AIDS.

The literature reviewed has not fully provided an understanding of the help-seeking behaviours of black African and African-Caribbean people in relation to late diagnosis and has also not provided sufficient information on variations in help-seeking between the two

groups studied and between men and women. To gain an understanding of the behaviours, the symbolic interactionist perspective (described in Chapter 3) together with the concepts of silences/broken narratives (Drakos 2008), biographical disruption (Bury 1982) and biographical abruptness (Locock et al 2009) (described elsewhere in this chapter) have been an inspiration in interpreting the findings.

2.3.14 Conclusion

Studies of help-seeking with black Africans and African-Caribbean people in the UK have mainly been quantitative (Burns et al 2007, 2008) and mostly retrospective in nature (Erwin et al 2002, Burns et al 2005). Other studies have focused on demographic characteristics at diagnosis (Fenton et al 2002) and ethnic differences at stage of presentation for diagnosis (Saul et al 2000, Boyd et al 2005). Although these studies have attempted to highlight some factors that affect help-seeking behaviours to diagnose HIV and AIDS, they have not considered other wider possible factors that may affect uptake of services for diagnosis of HIV and AIDS. Models of help-seeking (Rosenstock 1966, Mechanic 1968, Snow 1974, Zola 1973, Leininger 1991) have outlined factors that are likely to affect help-seeking. However, most of them do not provide a holistic view of factors that may impact positively or negatively on help-seeking to diagnose HIV. However, Kleinman's (1980) model and Leininger's theory (1991) have presented a more holistic view of factors that may influence help-seeking behaviours.

Although the biomedical model provides a basis for help-seeking, it appears insufficient because it does not account for wider factors that influence help-seeking to diagnose HIV and AIDS, with “a one size fits all” approach. It is hoped that my study will provide greater understanding of help-seeking behaviours of black African and African-Caribbean people to

diagnose HIV and AIDS. It is also hoped that this will provide baseline information to be considered in designing HIV screening programmes for black people³ in general. In order to explore patients' experiences, the current study takes a qualitative approach to probe into issues related to delays in seeking help. This carefully steps away from the usual concept of health-seeking rather to help-seeking. Health-seeking is grounded in biomedicine and help-seeking is more holistic, thereby considering biomedicine alongside ethno medicine.

³ Black people in this study, refer to black Africans and African-Caribbean populations.

Chapter Three

Methodology

3.1 Introduction

The previous chapter (Chapter 2) reviewed literature about help-seeking behaviour to diagnose HIV and AIDS. Public health and social science literatures were reviewed to summarise relevant existing knowledge about this subject area and to highlight the gaps that need to be addressed through an understanding of help-seeking behaviours of black African and African-Caribbean people to diagnosis HIV and AIDS. Public health literature showed that black Africans and African-Caribbean people present for diagnosis of HIV at an advanced stage of the illness with a CD4 count often lower than 200cell/mm³. It also highlighted that opportunities for diagnosis were often missed at medical consultations especially at the GP surgery. Social science literature showed that cultures and attribution theories influenced the decision and type of help sought.

The current chapter (Chapter 3) outlines the methodology that was adopted for this study. The interview method was the main method adopted. Interviews require a great willingness on the part of the participants to disclose their personal stories. In institutional settings or towards strangers such openness may be limited (Bergold and Thomas 2012). To facilitate such openness a ‘safe space’ for interviewing may be needed in which participants feel safe to share their personal stories and experiences and also where they are unlikely to suffer any disadvantage for mentioning their earnest opinions. It therefore outlines the issues of space

encountered for interviewing participants during fieldwork and describes how these issues were addressed.

Additionally, fieldwork is not always without dangers. This chapter therefore also briefly presents and discusses the potential dangers encountered during field work and how they were managed. Researching participants with similar ethnicity to the researcher can sometimes be challenging so this chapter highlights and outlines how social relationships were managed during field work. The chapter ends with measures to ensure the rigour of the methods used. A greater part of the discussions in this chapter has used a reflexive approach.

A reflexive approach can be described as the process of validating awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgment of the impossibility of remaining 'outside of' one's subject matter while conducting research (Malterud 2001, Sandelowski and Barroso 2002, Gilgun 2010). Reflexivity is the process that helps exploration of the different ways in which a researcher's involvement with a particular study influences, acts upon and informs such research (Nightingale and Cromby 1999). Willig (2001) suggests that personal reflexivity involves reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research. It also involves thinking about how the research may have affected and possibly changed us, as people and as researchers. Finlay and Gough (2003) suggest that in a qualitative study, the researcher should always examine how his or her inter-subjective elements can impact on and transform the research. Mason (2002) encourages researchers to be reflexive, not only as a means of thinking about and justifying what they are doing but also as a means of

confronting, challenging their own assumptions and recognising the extent to which their thoughts, actions and decisions shape what they research.

Stanley and Wise (1991) have observed that in many research texts, the ‘research process appears a very orderly and coherent process’ (1991:226). They describe such type of research as research that is described not experienced. Being reflexive therefore was a means of incorporating Mason’s idea and ensuring the trustworthiness of the methods used (Seale 1999), ‘experiencing’ the research and not ‘describing’ it as Stanley and Wise have highlighted.

A qualitative research approach was adopted based on a naturalistic interpretive paradigm (Denzin and Lincoln 2000). Strategies offered by naturalistic inquiry propose that realities under study are multiple, constructed and holistic (Maxwell 2012) as opposed to the ‘single, tangible and fragmentable’ (Lincoln and Guba 1985 p. 37) approach used in research based on positivist scientific rationale. The interpretive approach to research is based on the philosophy that counters the traditional positivistic approaches that are currently used in scientific research (Denzin 2001). Denzin in describing interpretive interactionism suggested that this approach is appropriate for exploring people’s personal experiences. This approach was therefore deemed appropriate for exploring the help-seeking behaviours of black African and African-Caribbean people to diagnose HIV and AIDS.

3.2 Positioning myself in the Research: Reflections on my ‘insider-outsider status

The status of the researcher as an ‘insider-outsider’ has gained some attention in qualitative discourse (Kanuha 2000, Sarrant-Green 2002, Dwyer and Buckle 2009, AL-Natour 2011). Before positioning myself in my research project, it is worthwhile understanding ‘the insider-outsider status. ‘Insider’ research refers to when researchers conduct research with populations of which they are also members (Adler and Adler 1994, Kanuha 2000). In this case the researcher may share an identity, language and experiences with the study participants (Ansselin 2000). ‘Outsider’ research refers to when the researcher is not a member of the population studied (Breen 2007).

I felt the need to position myself in this research as a means of ensuring rigour. Although I was an outsider to them in that I did not belong to the patient group, we shared a lot in common in terms of ethnicity and race. So I considered myself as having the dual status of insider/outsider. I also realised that I had another insider advantage that although I was not a member of the sexual health team, I was a member of the organisation that was being studied which gave me access advantage over a complete outsider. My organisational advantage was visible in the way I was treated by staff during the recruitment phase of my research by allowing me access into patients records on the grounds that I was a member of the organisation which was unethical because participants had not granted me access into their records. However, as will be seen later on in this chapter, this situation was well managed. Smyth & Holian (2008) warn against the risk that the insider-researcher gains access to sensitive information and advise on the need to observe ethical obligations.

In terms of ethnicity, I was an outsider to the African-Caribbean participants. These complex relationships complicated my insider/outsider status. This made me realize that if I continued to analyse many of our characteristics, I would be both an insider and outsider in many respects. Kusow (2003) has elaborated much on the complexity of this type of relationship. He suggested that the insider and outsider roles are ‘frequently situational depending on the prevailing social, political and cultural values of a given social context’. Merton (1972) provided further clarification by saying that individuals cannot be permanently located according to a single social status emphasizing that the same individual can occupy both statuses at different times.

Some advantages of being in the insider position included greater understanding of the culture of those being studied, the ease of establishing trust which promotes natural flow of interaction thus enabling the researcher to be able to tell and judge the truth (Bonner and Tolhurst 2002). I had added advantage as a member of the Organisation in that I knew, as Bonner and Tolhurst (2002) put it ‘the politics of the institution as well as the hierarchy and how it worked’. Smyth and Holian (2008) point out that it would take an outsider considerable time to acquire such knowledge of the Organisation. Other researchers (Dwyer and Buckle 2009), argue that insider research has the added advantage that participants feel that the researcher is one of them and will open up because they know that the researcher understands them.

As a black African, I had an insider advantage, for instance, of cultural knowledge which placed me in a position to understand the participants more than an outsider. Rhodes (1994) has carefully argued out this point by saying that there are some aspects of racial experiences that a researcher of a different race may not have, that could enable him/her to understand the participants. More importantly, an insider is in a better position to lead a successful

communication. However, I was aware of my insider position and was careful not to be too familiar as Hewitt-Taylor (2002) warns that such familiarity may result in the blurring of objectivity. Furthermore, some participants may not completely explain their experiences to an insider with the assumption that the researcher being part of them already understands (Dwyer and Buckle 2009).

Sarrant-Green (2002) highlights that, although there are arguments for outsider research, there are equally arguments against outsider research suggesting that one does not really have advantage over the other. While outsider research may sometimes be inhibitory, it may also be beneficial. Dwyer and Buckle (2009) suggest that one does not have to be a member of the group studied to appreciate and adequately represent the experiences of participants. They note that what is important in this case is not the ‘insider’ or ‘outsider’ status but the ability to be open, honest, reliable and deeply interested in the experiences of research participants and committed to accurately representing their experiences. For instance, Young (2004) notes that a few assumptions from insider/outsider debates conclude that outsider researchers find it difficult to gain the trust of their participants.

Based on my insider/outsider stance, some of my experiences during field work contradict this view. For example, one of my participants, a black African, before deciding to speak to me had declared on seeing me that she did not talk to Africans (despite my ‘insider’ status) and would rather speak with a ‘white’ person because they are not judgemental. This was one of the situations during which my dual position appeared rather inhibitory. Her decision to talk with me later might not have been because of my insider position but perhaps due to other personal characteristics.

My relationship with my participants sometimes appeared inhibited as a result of our closeness. My assumption that participants would be happy talking to me on the basis of my ‘insider’ status was therefore not entirely appropriate. For instance, one of the participants in my study ‘closed up’ and provided only one-word answers when he realised that we shared more in common than he had thought. Not only were we of the same race but we shared a common ethnicity, a common language and were from the same country with a common cultural background. This was however not surprising as Kusow (2003) has pointed out that as an insider after successful recruitment some participants may be uncomfortable and responses may be limited to short one-word answers which may lack enough details for an in-depth analysis. O’Connor (2004) asserted that this type of situation may be beneficial to an outsider as he/she will likely be keen to ask more questions to be sure of the clarity of what is being said. This type of behaviour can be related to the silences described by Drakos (2007) where he points out that people keep diagnosis secret as a way of avoiding suffering.

3.3 Theoretical Framework

In exploring the help-seeking behaviours of black African and African-Caribbean people in the UK, arguments have been based on a number of perspectives including the symbolic interactionist perspective (described in the next paragraph), broken narratives/silences (Drakos 2008), biographical disruption (Bury 1982) and biographical abrupton (Locock et al 2009) (described in Chapter 2).

3.3.1 Symbolic Interactionist Perspective

Symbolic interactionism (SI) is the product of the work of George Herbert Mead (1863-1931) which was elaborated and interpreted by Blumer (1900-1986), one of his students after his death. George Herbert Mead (1863-1931) aggregated and refined antecedent foundational work into a unique approach to the understanding of human behaviour (Blumer 1969, Meltzer et al 1975, Charon 1995). Blumer in elaborating the work conceived the word ‘symbolic interactionism in 1937 (Meltzer et al 1975, Charon 1995). The basic assumptions of SI conceptualized by Mead and elaborated by Blumer have developed into what is known as the Classical or Chicago school of Interactionism (Meltzer et al 1975).

The SI perspective is underpinned by three basic assumptions or tenets. These tenets hold that; 1. people either individually or collectively act on the basis of the meanings that things have for them, 2. that meaning arises in the process of interaction among individuals, and 3. that meanings are assigned and modified through an interpretive process which is ever changing, subject to redefinition, relocation and re-alignment of the things encountered (Blumer 1969). According to these tenets, human beings are capable of thinking and therefore do not simply respond directly to events and situations, but give meaning to them (Burbanks and Martin 2009). Behaviour or human action is based on meaning derived through interaction with one’s self and others. Blumer’s second tenet highlights that meanings are learned by human beings in the process of social interaction. Meaning emerges out of the ways in which other people act towards the person in relation to the thing for which meaning is being developed. These actions of other people serve to define the things for the person (Blumer, 1969).

Human beings are actors who are able to engage in self-talk. ‘The possession of a self provides the human being with a mechanism of self-interaction with which to meet the world, a mechanism that is used in forming and guiding his [or her] conduct’ (Blumer 1966, p.535). Thus, human action is caused by interaction among individuals, as well as by interaction within the individual. Charon (2007) in supporting Blumer’s tenet suggested that the continuous active on-going process of thinking or conversing with one’s self when alone and during interaction with others, is key to understanding action. A symbolic interactionist perspective aims to facilitate the understanding of the behaviours of the two groups studied by exploring their help-seeking approaches and the meanings attached to their behaviours.

3.4 Research Design

The help-seeking behaviours of black Africans and African-Caribbean people to diagnose HIV and AIDS were explored using a qualitative research approach. The design is cross-sectional. The choice of this approach was supported by the need to capture participants’ perspectives and to understand these perspectives through detailed interviewing. This approach draws from interpretivism which assumes that there is no objective knowledge independent of thinking (Mason 2002, Maxwell 2012). Reality is viewed as socially and societally embedded, and existing within the mind (Denzin and Lincoln 2008). These realities are fluid and changing (Mason 2002), and knowledge is constructed jointly in interaction by the researcher and the participant through consensus (Denzin and Lincoln 2008). Interpretivists suggest that knowledge is subjective, constructed and based on the shared signs and symbols which are recognised by members of a culture (Maxwell 2012). They also suggest that multiple realities are presumed with different people experiencing these realities differently (Grbich 2007). By positing a reality that cannot be separated from our knowledge

of it, the interpretivist paradigm assumes that the researcher's values are inherent in all phases of the research process (Grbich 2007).

According to Max Weber (1949), the social world cannot be described without investigating how individuals use language and symbols to construct what social practices and experiences mean for them. It is by understanding the individual experience and its subjective interpretation that an understanding of why social actors behave in particular ways begins to emerge. Interpretivism seeks to understand and not to predict and explain, and such understanding begins from the presupposition that there is some common ground between the researcher and the researched. Furthermore, in qualitative methods, the use of inductive analysis begins with the data itself (Dey 1993) and it is from these data that rational propositions and theories are arrived at by the inductive reasoning processes.

A quantitative approach was unsuitable for this type of study because it is seldom able to capture its subjects' perspectives since it has to rely on more remote, inferential empirical methods and materials (Denzin and Lincoln 2000). Through a qualitative approach the interviewee is allowed to 'tell the story' by the use of open ended questions (Field and Morse 1985, Patton 2002) with the opportunity for the interviewer to probe and get the interviewee's own perspective. This allows the researcher to remain open to what emerges from the investigation (Patton 2002). The use of the interpretive inquiry in natural settings such as the clinical setting has been seen as a realistic way of making sense of, and interpreting meanings that people might bring to their personal experiences through interviews with participants (Denzin and Lincoln 1994) for the purpose of the study.

Using a qualitative approach especially one which involves direct patient contact has its own shortcomings, some of which include issues with role identity and therapeutic misconception. Understanding the dual role of the researcher as a nurse and as a researcher may not only be an issue for the nurse (Holloway and Wheeler 2002) who may not understand that the nurse's clinical role has to be separate from the researcher role when she/he is conducting research except in exceptional circumstances. Morse and Field (1996) suggest that patients may also not understand the role and will expect empathetic nursing care even from a professional who happens to have the title 'researcher'.

However, some people have argued that even while undertaking a researcher role, the clinical underpinnings cannot be completely divorced (Colbourne and Sque 2004) by the nurse. This argument is based on the fact that the nurse-researcher has a professional responsibility to intervene if there is an immediate threat to the health and safety of the participant and she/he has the professional skills to cope with such a threat (Field and Morse 1985, Jack 2008). This is important because the nurse's code of conduct requires some action by the nurse in such circumstances in order not to be in a breach of the nurse's code of professional conduct for an act of omission (NMC 2008). Because situations are likely to arise that need the nurse's intervention, what is important here is that the nurse should be aware of the limits of the two statuses (researcher and nurse) and should be clear about the line of action in case such situations arise. In order to maintain rigour, some authors advise that the nurse-researcher while in a researcher role should only intervene clinically at the end of the research encounter unless the situation is life threatening (Swanson 1986, Cartwright and Limandri 1997) and needs intervention.

Conflicts that can occur in such situations require a balance between research integrity and the welfare of the individual. This is likely to become even more daunting especially if the researcher is conducting the research on his/her own unit. The question that arises is about the effect on the data if a nurse-researcher decides to intervene or is asked to provide health information during an interview. Some authors (e.g. Field and Morse 1985, Chenitz 1986, Hutchinson and Wilson 1994) specify that the primary objective of a research interview is to collect data and not to offer intervention as this may threaten the validity of data. However, Britten (1995) suggested that if intervention involves the request for health information this should be deferred to the end of the interview although with the view that refusing to answer clinical questions or concerns may impact negatively on the interview. There are other suggestions that in such circumstances the nurse-researcher should refer the participant to another health care professional than deal with the issue himself/herself.

On the other hand, the subjective nature of the researcher-research participant relationship may suggest that intervening during an interview enhances rather than threatens the validity of the data (Hall and Steven 1991, Oakley 1993). Some authors like Wilde (1992) have suggested that intervening during an interview may open up new areas for inquiry and exploration.

3.4.1 Research Setting

The research participants were recruited at two GUM clinics in London. For the purpose of this study and for clarity, the two clinics will be referred to as Clinic A⁴ and Clinic B⁵. The Clinics are used interchangeably with the sites in this chapter. As these were clinical settings,

⁴ Clinic A is at Site A.

⁵ Clinic B is at Site B.

it was important to be aware of problems that are inherent in researching in clinical settings. Estroff and Churchill (1984) identify ‘being caught up’ between staff and patients as one of the common problems for researchers in the clinical setting and suggest that a reporting process to resolve this type of situation be established at the outset. Initially recruitment was planned only for Clinic A. Subsequently, there was need for recruitment at Clinic B located in a second hospital although this hospital is still part of the same National Health Service (NHS) Trust. The original site for this study was Clinic A in a large NHS hospital located in an area with a large black ethnic population⁶ in the outskirts of London. The choice of this particular locality was influenced by the researcher’s familiarity with both the environment and the NHS Trust. This was one of the advantages of being an insider. This site is well accessible through local buses and trains. The clinic in site A provides sexual health services to several patients a year including those seeking HIV and AIDS care.

An NHS hospital was chosen under the assumption that many black Africans and African-Caribbean people are economically disadvantaged people and for health issues would prefer attending NHS hospitals where the otherwise non-affordable antiretroviral medications are provided for free. A black ethnic dominated area was chosen in order to have a sufficient and diverse black African and African-Caribbean sample. Clinic A was quite spacious in layout and space but less busy in terms of the number of patients that attended for HIV and AIDS care compared with clinic B. For instance statistics at the clinic indicated that during the period from the 1st of January 2009 to the 31st of December 2010, a total of 355 patients were seen at this clinic for HIV and AIDS diagnosis and care. Among these patients 45 were white (ethnicity not broken down), 15 of them Asian (ethnicity not broken down) and 295 were black Africans and African-Caribbean people. Comparatively this number is less than the

⁶ Black ethnic populations in this context refer to black Africans and African-Caribbean populations.

number of patients seen at clinic B during the same period as is presented in the next paragraph.

The layout of clinic A favoured participants' recruitment by the researcher. Most patients who came through the clinic were noticed by the researcher and this provided an opportunity to follow up with the nurse to ascertain their eligibility for the study. There was clear indication that most patients did not feel at ease walking through the clinic itself as they did not seem to want to be seen by anyone outside their treating team. Although this feeling was verbally expressed by some of the participants during interview sessions, it was also evident in the way some of them waited to be seen with their heads bowed. Chapter Two has highlighted that HIV positive people want to appear normal and therefore tend to conceal their diagnosis (Drakos 2008) and as will be seen later in the findings they may even falsify their true diagnosis.

Clinic B was also located at an ethnically diverse area still in London. From statistics at the clinic, during the period from the 1st of January 2009 up to 31st December 2010, the clinic at site B provided HIV and AIDS diagnosis and treatment to approximately 455 patients among whom 325 were black Africans and African-Caribbean people (Table 1), 77 patients with a white background and 53 of them of Asian background. The total number of African-Caribbean and black African patients seen in Clinic A and Clinic B for HIV and AIDS care from January 1st 2009 to December 31st 2010 is summarised in table 1 below. The choice of this clinic was also influenced by familiarity with both the environment and the NHS Trust itself. Even though there were many more patients that attended clinic B than they did at clinic A, there was a greater Asian and white populations at this clinic than at clinic A where

the black African and African-Caribbean populations appeared to be greater than the White and Asian populations that attended for HIV and AIDS care.

	Clinic A			Clinic B			Grand
	Men	Women	Total	Men	Women	Total	Total
Africans	74	142	216	106	173	279	495
Caribbean	40	39	79	23	23	46	125
Total	114	181	295	129	196	325	620

Table 1: Total number of African and African-Caribbean people seen in Clinics A and B for HIV and AIDS Care from January 1st 2009 to 31st December 2010

3.4.1.1 The hospital as research setting.

The impact of the research setting on respondents can never be overlooked. In health care conducting interviews on participants in the clinical setting may be challenging. This may become even more difficult if the research involves a sensitive topic. McCosker et al (2001) suggested that a subject of research is described as "sensitive" if it deals with issues that are private, stressful or sacred, and their discussion tends to generate an emotional response, for example, death and sex, as well as phenomena that deal with potential fear of stigmatisation, such as HIV and AIDS. I was researching experiences related to HIV and AIDS which is not only a sensitive area but is also stigmatising. The choice of the clinical setting as a suitable place for conducting interviews was one of the REC's conditions for approval as a result of the sensitive nature of the subject. This was a way of assuring the safety of participants and researcher as well as their confidentiality. Also, it was the natural setting where research participants obtained their treatments.

Nevertheless, the hospital environment as a research setting may appear intimidating to the participants. This type of feeling may invoke the feeling of power differential between the researcher and the participant who may feel compelled to take part in the research. Such feelings are highly likely to cause the participant to be less open (Eggenberger and Nelms 2001) than would probably have been the case if they were interviewed in a public place or in their home.

Some researchers (e.g. Eskola and Vastamaki 2001, Adler and Adler 2002) suggest that with research that has a sensitive and an emotive element, it is rather appropriate to conduct interviews in the participants' home or in a private area. Interviewing participants in their homes may be ideal as the participants remain in their natural environment but the home environment especially in sensitive areas like the one being studied may be unsafe for both the researcher and the participant. Research on sensitive topics can entail risks such as breaking confidentiality when sharing information that reveals some intimacy (McCosker et al 2001, Corbin and Morse 2003, Dickson-Swift et al. 2009) which may be information that other family members may not have known. For this research, the hospital was the place where the confidentiality of information and privacy of the participants could be assured.

However the impact of the hospital setting on the responses may have been both positive and negative. For instance, conducting interviews with participants where they received their treatment implied that their confidentiality was maintained and they probably felt more relaxed to tell their story than might have been the case if they were interviewed elsewhere. I also wonder if the responses would have been different if they were interviewed in their homes. I was a nurse interviewing them in the hospital and wonder how they perceived me

and if my position as a nurse influenced their responses. It is possible that if they were interviewed in their own homes or by a non-professional the results might have differed.

3.4.2 Gaining Access

I had imagined that negotiating for access would be quite challenging being an ‘outsider’ in sexual health issues and to the clinic itself. Such imagination was based on the awareness that gaining access to a research setting and to the research participants can be a daunting process although it is an important step in the research process (Burgess 1984, Van Maanen 1988, Feldman et al 2003, Shenton and Hayter 2004, Creswell, 2008). Gaining access becomes even more difficult if the subject of research is a sensitive area (Renzetti and Lee 1993, Melrose 2002, Dickson-Swift 2005, Okumus et al, 2007) such as the one that was being studied. However, negotiating access on this occasion, turned out to be an interesting phase of the whole journey as I was given ‘too much access’. A letter of request for access to the genito-urinary medicine (GUM) clinic was sent to the Consultant Physician in charge of the clinic together with the study proposal and the ethics approval letter. Publishing in a peer reviewed journal and storing data at the clinic at the end of the study were the gatekeeper’s conditions for granting access to the research setting and the gatekeeper eventually became my clinical supervisor, a condition for Research and Development (R&D) approval.

Granting access to research participants in return for some conditions to be fulfilled by the researcher is not new. Some researchers (e.g. Hall and Hall 1996, Laurila1997) highlighted that some gatekeepers granted access to research participants on condition that they provided something in return. Access to research participants in some instances is ensured if the investigator agrees to share his/her findings and papers that emerge from the research with the collaborating organisation (Sharp and Howard 1996). Other issues identified by Gorman

and Clayton (1997) and Bogdan and Biklen (1998) to be clarified by the investigator before being granted access to the research setting include a justification of choice of fieldwork sites, the specific work that would be done, the extent of any anticipated disruptions and reporting plans.

Negotiation for access continued at the clinic on Site B⁷ as the need to extend recruitment to a second setting arose during the course of the study. Feldman et al (2003) assert that seeking access continues throughout the whole study and some researchers (e.g. Hall and Hall 1996) have identified that negotiating for access may sometimes be a lengthy process. However the process was quick as part of the team at Site B also worked at Site A⁸ and was already aware of the project. The required letters for access and the requested documentation were submitted to the head of department at Site B. This is a non-substantial amendment and therefore did not require submission to the Research Ethics Committee (REC) for approval. A substantial amendment is one that involves any modification to the protocol or to the main study documents. However, the REC was notified for information purpose only. The Research and Development department required written permission from the head of department at Clinic A as well as the written permission of the onsite supervisor confirming their satisfaction with this arrangement. However, the process was short as I did not require a research passport or a Site Specific Information (SSI) Form being an employee of the Trust and the study was Site Specific Assessment (SSA) exempt.

In addition to controlling access to the participants, gatekeepers control the flow of interaction within the research setting (Burgess 1991, Shenton and Hayter 2004). I solicited

⁷ Clinic B was the additional study Site.

⁸ Clinic A was the original Site for the study.

participants by liaising with the staff (doctors, nurses, health advisors and the manager) at the GUM clinics after receiving ethical as well as R&D approvals as these were the key to penetrating the gatekeepers, and by attending the clinic to contact potential participants with the help of the clinic staff.

Attendance at the clinic started with a brief presentation on my subject area to the staff during their weekly meetings. These were regular meetings intended for educational purposes. This forum was used as an opportunity to introduce myself, my subject area and while not only familiarising myself with the team, my intended outcome, was to spell out what I intended to do at the clinic as well as my expectations. This was the period that Lincoln and Guba (1985) describe as the period of ‘orientation and overview’ which is the period during which the investigator develops rapport and gains the trust of potential informants. This was also seen as part of the process described by Feldman et al (2003) as ‘legitimizing the researcher,’ a process to demonstrate to the gatekeeper that the investigator is a credible researcher who is professional. Morse and Field (1996) and Hays and Singh (2012) emphasise the importance of keeping the personnel at the research site updated of your schedule and progress to gain their trust. They also emphasise the need for the researcher to acquire the skills of being present and being trusted without being close to one particular person or one particular subgroup. In their words: “be like the group one is studying yet paradoxically to keep one’s distance” (Morse and Field 1996 p. 58).

Although my initial talks during these weekly meetings were often brief, they had a positive impact on my confidence in subsequently conducting the interviews. In spite of the difficult start, I quickly gained the trust of staff to the point where it was suggested that I access patients’ records to identify potential participants myself than relying solely on them for this

assignment. A good relationship had developed between the staff at the clinic and me to the extent that I was given too much access. Feldman et al (2003) have suggested that establishing a good relationship in the field can enable researchers to gain more access than they really expected. Although it was unethical for me to access patients' records for their personal information without their prior consent (Beauchamp and Childress 1994) since I was not part of the treating team, some staff at the clinic found it difficult to understand and insisted that I could access patients' records without any questions. Their assumption was probably that my status as an employee of the Trust (insider) gave me automatic access to information about patients whose care I was not involved in. Such an act would constitute a breach in confidentiality and disrespect of patients' rights. This left me feeling that I had 'leapt' from the struggle to gain access, to being given too much access. This together with an apparent lack of some staff knowledge of ethical issues would have compromised patients' confidentiality on my part; but this was well managed by discussing with the staff the importance of respecting patient's confidentiality.

3.5 Target Population and Recruitment

The target populations were black African and African-Caribbean men and women receiving care for HIV and AIDS at the two clinics. The sample comprised 33 HIV and AIDS positive participants aged between 18 years and 50 years. This age group is considered more sexually active and consequently has a higher probability of getting infected with the HIV virus. Initial plans were to recruit 35 participants, with three of them being recruited during the pilot phase, but it proved difficult to achieve the targeted sample size. Recruiting participants can be a challenging exercise. This difficulty may be compounded by the nature of the research subject and especially if it is a sensitive or stigmatising area like the subject of my research.

Ashery and McAuliffe (1992) highlighted that recruitment problems can disrupt the research timetable. The pilot phase aimed to pre-test the research instrument (Baker 1994, Schreiber 2008) and to make any necessary adjustments but no adjustments were necessary at this stage. De Vaus (1993:54) considers this phase important and cautions against taking risk by saying '*do not take the risk; Pilot test first*'. Included participants were 16 males (eight black African and eight African-Caribbeans) and 14 females (eight black African and six African-Caribbeans). One of the objectives of this study was to compare help-seeking behaviours of black Africans and African-Caribbean people and of men and women and therefore there was a need to have an approximately equal number of participants in each group and sub-group although Brannen (2005) suggests that having an equal number of participants in each sub-group is not important. However, this was not possible as the female African-Caribbean sub-group was difficult to recruit. Recruitment proved challenging in the beginning perhaps because I was still setting up a pattern to follow.

As mentioned earlier in the chapter, I had assumed that because I was researching a group with whom we shared much in common, they would be eager to participate in the research project. Paradoxically, recruitment proved difficult. Perhaps there might have been some insignificant amount of self-selection since it is believed that there is always some amount of self-selection in research that is voluntary but this was not clearly evident. Some potential participants may not have been interested in taking part because of their prior experiences in the clinical setting. For example, one of the participants although she agreed to be part of the study, on seeing me had reacted by saying that she did not deal with Africans because of a prior experience in the clinical setting involving an African, but later agreed to be part of the study. Moreover, recruitment was based on strict inclusion and exclusion criteria which were respected. Although this may seem to contradict the experience of some qualitative

researchers (Hurst 2008), this may probably have been so because of the sensitive nature of the subject area that was being researched which explains why some potential participants who fulfilled the inclusion criteria were not interested in taking part in the study.

The criterion of the ‘period of time since diagnosis’ was also a limiting factor as there were many patients diagnosed more than three years at the time of the study. Many of those diagnosed less than a year appeared less willing to participate in the study. Dickson-Swift et al (2008) and Lee (1993) highlighted that doing qualitative interviewing on sensitive subjects such as this one being studied is capable of eliciting emotions in the participants by bringing back feelings that they might be trying to repress. This slowed down recruitment of participants at this clinic and therefore resulted in the need to extend recruitment to include clinic B based on similar inclusion and exclusion criteria. Recruitment problems here were similar to those at clinic A. Another factor that potentially slowed down recruitment was the linguistic factor. Only those who could speak English were included in the study. In hindsight, I feel that this was an opportunity for me to make use of my linguistic abilities as I could read and speak French and could have included potential French speaking participants.

The sub-group of participants that was most difficult to recruit was the female African-Caribbean sub-group as is reflected in the number of participants from this sub-group that participated in the study. There are several possible reasons for the difficulty in recruiting this sub-group. From my observation at the time of the study, fewer female African-Caribbean patients attended both clinics compared with the other sub-groups which could mean that perhaps they are less infected with HIV and AIDS than the black African women who came in their numbers. It is also possible that they were not presenting themselves for diagnosis. Some of those who attended did not fulfil the inclusion criteria.

Ochieng (2010), a black African woman researching black African families, reported a positive experience in her interaction with the families but the difference in her experience and mine could be attributed to their similarities in ethnicity. From a personal experience, in October 2010 during the Mary Seacole Award⁹ Ceremony, two cheerful African-Caribbean women walked up to me in the exhibition area at different times and surprisingly they both reminded me that we are still sisters because they still see themselves as Africans even though they were ‘sold out’ by African people. Could similar feelings in potential participants have impacted negatively on the recruitment of this sub-group of participants? I had not had a prior conversation with them to enable them to possibly determine my ethnicity from my accent. It is possible that there were similar feelings among some potential participants that attended the clinics and this might have affected the recruitment of this sub-group.

3.5.1 Sampling Method

The clinics and participants were purposively selected from a group of patients attending the GUM clinics for HIV and AIDS treatment at the NHS hospital in question. This was done in order to reflect characteristics such as age, ethnicity and gender in line with Morse (1991) who suggested that sampling be both appropriate (i.e. method fits the aim of study) and adequate (i.e. generates adequate and relevant information). Creswell (2007) discussed the importance of selecting the appropriate candidates for interviews. He suggests that the researcher should utilize one of the various types of sampling strategies such as criterion based sampling in order to obtain suitable participants who would provide the required information in an open and honest manner. Through purposive sampling, the staff at the

⁹ The Mary Seacole Award is an award given to Nurses in honour of the ‘black’ nurse Mary Seacole for her leadership and endurance despite racism during the Crimean War. This award enables nurses to enhance their leadership skills through projects that benefit minority groups in the UK.

clinic identified those who were eligible and referred them to me. Having been allocated a room to recruit and carryout interviews, I visited Clinic A on average twice a week, during which potential participants were being identified by clinic staff from the daily appointment lists and referred to me for recruitment.

A similar schedule was employed for Clinic B. The sample size was small and not intended to be representative of black African and African-Caribbean groups in statistical terms but using the logic of qualitative inquiry, more interest was in understanding the different meanings of the narratives of the different individuals than being able to generalize those experiences to a larger population. However, there have been a number of debates on the size of the sample in qualitative research but many researchers (Adler and Adler 1987, Charmaz 2006, Small 2009, Mason 2010, Flick 2011, Bryman 2012) argue that what is important is not the size of the sample but the saturation of data.

The notion of saturation derives from Glaser and Strauss's (1967) account of grounded theory where they describe theoretical saturation as the process in which the researcher continues to sample relevant cases until no new theoretical insights are gathered from the data (Bryman 2012). However, some qualitative researchers give numerical guidance and point out that this is a requirement for REC approval at the research proposal level. For instance, Adler and Adler (1987) propose a sample size of 12-60 in qualitative studies, with 30 being the mean. They suggest that the difficulty in gaining access, the time available to conduct the research, the difficulties in transcribing many interviews and the obligation to publish may justify such a sample size in inductive research. Similarly, Warren (2002) talks about 20 to 30 and Gerson and Horowitz (2002: 223) suggest that 'fewer than 60 interviews cannot support convincing

conclusions and more than 150 produce too much material to analyse effectively and expeditiously'.

Other researchers (e.g. Brannen 2005, Becker 2007) suggest that as little as one interview maybe enough. Patton (1990) noted that the key to purposive sampling is to select cases for systematic study that are information rich and argued that the sample should be determined on the basis of information needs till no new information is obtained (data saturation). Too small a sample size can lead to misleading results and too large a sample size may make in-depth analysis of each case difficult (Gerson and Horowitz 2002, Bailey 2007). Brannen (2005) emphasised that there is no specific rule about sample size in qualitative research or distribution of number of persons within a group but that what matters is the purpose of the research, the type of research question to address and the methodology to be adopted.

Apart from the methodological and epistemological perspectives considered other factors that may determine sample size have been termed by Flick (2008) as 'outside determinants'. These include the time available to complete the research project, the ability to find and keep in contact with participants, funded research where there are enough funds to hire interviewer and to pay subjects as well as institutional ethics committee demands. Similar to Baumberg (2006) who highlighted the difficulties in accessing patients especially when the NHS is involved, Adler and Adler (1987) noted the difficulty in recruiting a big sample when researching groups such as illegal, deviant and vulnerable populations.

My participants were not only being recruited in the NHS but they were also a vulnerable population. The sample of 35 was previewed based on their vulnerability as well as the expected variability of the sample. While I genuinely wanted to understand the help-seeking

behaviours of black Africans and African-Caribbean people to diagnose HIV and AIDS, I was also aware that the area I was researching was a sensitive one and had mixed feelings about whether I would have a reasonable sample size to help my understanding of the issue in question. However, although attaining the required sample size was difficult, the decision to stop at a sample size of 33 was dictated by all indications that data saturation had been attained. Bryman (2012) suggested that the heterogeneity of the population with sub-group variability may influence sample size. My aim was to capture variability in experiences and views of participants from black Africa and the African-Caribbean people and of men and women.

3.5.2 Socio-demographic characteristics of the participants

The actual sample comprised 30 participants. All the participants were aged between 23 and 50 years with 10 of them aged between 40 and 49 years and 15 of them aged between 30 and 39 years. Only two participants were aged between 20 and 29 years and three of them were aged 50 years old. Of the 30 participants, eight were less than a year into their diagnosis, six were a year into their diagnosis, five were in the second year of diagnosis and eleven were in their third year since diagnosis. These characteristics are summarised on Table 2 below.

Items	Description	N (%)
Age groups	20 – 29years	2 (6.7%)
	30 - 39 years	15 (50%)
	40 – 49years	10 (33.3%)
	50years	3 (10%)
Ethnicity	Caribbean	14 (46.7%)
	African	16 (53.3%)
Gender	Men	16 (53.3%)
	Women	14 (46.7%)
Marital status	Single	12 (40%)
	Married	11 (36.7%)
	Divorced	6(20%)
	Widowed	1 (3.3%)
Employment	Employed	18 (60%)
	Unemployed	12 (40%)
Length of time since Diagnosis	< 1year	8 (26.7%)
	1 year	6 (20%)
	2years	5 (16.7%)
	3years	11(36.6%)

Table 2: Demographic characteristics of Participants

3.6 Ethics Approval Process

Ethical approval was obtained from the relevant Research Ethics Committee (REC) and research and development approval from the NHS Trust's Research and Development (R&D) Committee of the Hospital where the study took place, through an application. An Integrated Research Application System (IRAS) form was completed and submitted online with a consequent generation of a REC reference number. This, together with the required documentation was submitted to the relevant ethics committee. A REC meeting was scheduled to hold after three weeks of the receipt of the application. Few and minor amendments were required but approval was granted during the meeting.

A research management approval was also required and an application, together with the required documentation which included the ethics approval letter was submitted to the R&D committee. Conditions for approval included successful completion of the Good Clinical Practice (GCP) course online as well as submission of a signed code of conduct form. Approval to carry out the research was granted forty three days after submitting all the required documentation and fulfilling the required conditions.

These enabled the researcher to contact the research participants at the clinics. The privacy and confidentiality of the research participants was respected and their informed consent was obtained before engaging them in any interviews (Hulley et al 2001). Also anonymity was assured by coding the transcripts and participants were reminded of the ability to withdraw from the study at any time. Participants were also informed that transcripts would only be seen by the researcher and her supervisors and all the tapes and transcripts would be stored under lock and key and would be destroyed after ten years of completion of the study.

This study was conducted according to the guidelines established in the Declaration of Helsinki (52nd WMA General Assembly, Edinburgh, Scotland, October 2000 [Note of clarification on Paragraph 29 added by the WMA General Assembly, Washington 2002]) and in compliance with recognized Good Clinical Practices (GCP). Patients were free to withdraw from the study at any stage without prejudice to their subsequent treatment.

GCP is an international ethical and scientific quality standard for designing, conducting, recording and reporting studies that involve the participation of human subjects. This course was undertaken online as one of the conditions for R&D approval. The study was conducted in compliance with GCP and the applicable national regulations so as to assure that the rights, safety and wellbeing of the participating study subjects were protected consistent with the ethical principles that have their origin in the Declaration of Helsinki.

3.7 The Informed Consent Process

In accordance with the ethical principle (Beauchamp and Childress 1994) which stresses respect for potential participants, we went through a consent process before interviewing each of the participants that was willing to participate in the study. Informed consent can be described as the process by which a fully informed individual voluntarily decides whether or not to take part as a research participant (Patel et al 2003). During this period I ensured that the participant had understood all the information (both written and verbal) about the study and also all about what their participation in the study entailed and was willing to participate (Kvale and Brinkman 2008). I also gave them the opportunity to ask questions and if they were happy with what their participation involved, we then went through the consent form and if they agreed they then signed the consent form. The informed consent process took

place under conditions where the subject had adequate time to consider the risks and benefits associated with his/her participation in the study. Subjects were not interviewed until the subject had signed an approved informed consent written in English and understandable to the participant. The ethics committee approved informed consent form was signed and personally dated by the subject and the researcher who conducted the informed consent discussion. A copy of the consent form was given to them and the original copy filed in the research documentation folder. A log of all subjects who signed the informed consent form was also maintained.

3.8 Data Collection Procedure

Data was collected by the use of semi-structured interviews to allow flexibility and the possibility of following the interests and thoughts of the participants (Holloway and Wheeler 1996). Creswell (2007) suggested flexibility in the construction of research questions asserting that respondents in an interview will not necessarily answer the question being asked by the researcher and may answer a question that is asked in another question later in the interview. This method also allows the respondents to tell their stories in a naturalistic, narrative fashion (Polit et al 2001). Kvale (1996 p.1) suggested that ‘if you want to know how people understand their world and their life, why not talk to them’. Ochieng (2010) highlighted that an over prescriptive way of asking questions poses the danger of loss of meaning as the researcher is unable to explore in detail the issue in question to gain a greater insight. Although semi-structured interviews generate rich data, its limitation is that it may also generate some irrelevant data (Patton 1990). This was overcome by refocusing the participants by the use of probes and prompts. Gray (2004) has suggested that probing is a

way for the interview to explore new paths which might not have been initially considered.

O'Leary (2004:162) stated that;

'Interviewing has its own issues and complexities and demands its own type of rigour'.

Interviews were conducted only by the researcher and at a time agreed with the participant and all interviews took place at the clinics during clinic hours. Field and Morse (1985) recommended an hour for each interview even though the length of the interview depends on the informant. However, some of the interviews lasted less than an hour but the average interview time was 45 minutes. I ensured that I went through the interview guide and explored any emerging themes during the interviews.

All the participants appeared physically fit so there were no breaks during the interviews. Holloway and Wheeler (1996) suggested the possibility of breaking an interview after half an hour during interviews with sick, elderly and young children. Interviews were recorded with the permission of the participants in line with the principle of respect for autonomy (Beauchamp and Childress 1994) and later transcribed verbatim by the researcher. Holloway and Wheeler (1996) encourage transcription by the researcher as this helps immersion in the data. Transcription was done soon after recording the interviews to facilitate understanding of the data. Personally transcribing the interviews also ensured the confidentiality agreed with participants. All transcripts were coded and these together with the analysis were void of any information that identified participants.

Data collection started in May 2009 and ended in December 2010. Interviews were conducted on a one - to - one basis using open ended questions aimed at allowing participants to tell

their story. Kvale and Brinkman (2008) recommended short and simple questions. This technique worked well as some of the participants did not have English as their first language and short and simple questions were easy to understand. Field notes of important points mentioned before, during and after the interview were kept after each interview. Hamersley and Atkinson (1983) and Hays and Singh (2012) pointed out that recording field notes constitute a central research activity and Hughes (1994) suggested that the quality or adequacy of a research project is not only the results of the questions asked or concepts used, but it is also the result of keeping rigorous field notes. This was followed by preliminary analysis to keep track of the ideas emerging (Silverman 2000) and to enable further exploration during subsequent interviews.

Whilst devising the interview schedule, I was aware of how each question could be evaluated from a thematic perspective. My interviewing ‘adopted conversational characteristics’ (Kvale and Brinkman 2008, p. xvii) although it maintained a systematic approach recommended by Seidman (1991). Kvale and Brinkman (2008) suggested that interviewing involves a cultivation of skills and further explain that interviewing using a conversational style helps the researcher to know the participants, ‘learn about their experiences, feelings, attitudes and the world they live in’. I allowed pauses during interviewing as this allowed the participants to think about their responses and also put them at ease. At times I paraphrased what the participants said to ensure that I understood them and repeated my questions if they expressed lack of understanding.

Each participant in the study was interviewed once. Brannen (1988) recommends only one interview and suggests that interviewees are likely to open up to the interviewer in a one off interview encounter. Seidman (1991) on the other hand advocates three interviews and

Cornwell (1984) and Oakley (1981) from their experience of interviewing, support the idea of conducting more than one interview with the same participants. They argue that first interviews are not as rich as subsequent interviews with the same participants because participants build a trusting relationship with the researcher and are able to tell their story. Although conducting interviews more than once may have advantages, there may also be some draw backs. For example, some participants may be left feeling that they have given out too much about themselves (Dickson-Swift et al 2008). Perhaps conducting more than one interview would have been ideal especially as the subject was sensitive and a trusting relationship would have enabled the participants to be freer in disclosing their experiences. For instance, one of the participants disclosed issues around the intimacy of her sexual relationship with her HIV negative partner. A trusting relationship had started building up between us which enabled her to give out such intimate details. Some researchers (e.g. Booth and Booth (1994), Fontana and Frey (2005), Dickson-Swift (2005) have pointed out that such a relationship is crucial to the success of the research. The inability to conduct more than one interview was related to the sensitive nature of the subject, the short time span available to carry out the study and the difficulties involved in organising appointments with the groups of participants studied.

In order to understand the participants' perspective, the interviews focused on participants' stories (Seidman 1991, Kvale and Brinkman 2008) using open ended questions and probing and prompting where appropriate to enable elaboration, meaning and reason and in some cases to reduce both the researcher and the participant's anxiety (Holloway and Wheeler 1996). Flexibility and consistency were balanced (May 1991) to enable comparison of the accounts of individuals without neglecting the unique stories of their experiences.

3.8.1 Other Possible Methods

3.8.1.1 Focus Groups

Focus group interviews would possibly have been a good method to collect data for this study as it offers the opportunity for interaction (Kitzinger 1994, 1995) by group members although its appropriateness remains ambivalent in sensitive research. Tonkiss (2004) asserts that individual interviews and not focus groups are ideal in sensitive research maintaining that the nature of the subject and the group composition are the main determinants of people opening up in a focus group situation. Kitzinger (2002) on the other hand challenges this view and justifies the appropriateness of focus groups in sensitive research by pointing out that interpersonal dynamics within the group have the potential to enable participants to gain mutual comfort and reassurance and therefore the tendency to open up.

However, this method was not only inappropriate for the area being researched but it was also challenging in this case because of the difficulty in getting the participants together. Some of them were employed and their hospital appointment dates and times varied making it difficult to have a group to conduct a focus group interview. Additionally, most of those who participated in the study expressed that they did not want to be seen at the clinic even by other patients because of the high possibility of unintended disclosure. The sensitive and stigmatising nature of this subject therefore made the use of focus groups interviews unsuitable as it is possible that participants might not have wanted to publicly express their views or share their experiences in a group situation (Morgan 1998). Additionally, compared with individual interviews, focus groups may not be efficient in covering maximum depth in a sensitive subject like the one studied and the issues of anonymity and confidentiality

(Homan 1991) may not always be guaranteed. However, focus group has the advantage that it is less time consuming and less costly.

3.8.1.2 Questionnaires

It was possible to use questionnaires as another method of data collection for this study but questionnaires were not explored in depth because they often do not give room for participants to express themselves fully and because response rate from this method is often significantly lower than with interviews even though they are less costly, less time consuming and offer the possibility of anonymity (Polit et al 2001). A larger representative sample size typical of quantitative research designs would have been required to reach conclusions on this topic. Significantly, questionnaires may be limiting in this type of study as they do not offer the possibility of probing further into the participants' experiences to gain further insights. My objective was to understand the help-seeking behaviours of black Africans and African Caribbean people to diagnose HIV and AIDS. Therefore the use of questionnaires did not seem appropriate for this particular study.

Field and Morse (1996) and Dickson-Swift et al (2007) identify that data collection can become a time of intense emotional strain with the participants stories haunting the researcher. Johnson and Clarke (2003) highlighted that undertaking research with vulnerable groups; can present some emotional difficulties both for the researcher and the researched. I was able to overcome this as interviews were spaced giving me time to reflect on participants' experiences. This together with a full time job provided a source of distraction. In some cases, to reduce emotions in the participants and engage them to tell their story, I started the interaction by telling them a story. Such a strategy had the effect of making them eager to tell their personal stories. Gilbert (2001) points out that a fundamental aspect of

being human in such situations is the capacity to feel and show emotions. I found this necessary during interviewing as the participants felt supported when emotions were manifested.

Gilbert (2001: 9) has suggested that as qualitative researchers,

'our goal is to see the world through someone else's eyes, using ourselves as a research instrument; it thus follows that we must experience our research emotionally too. As researchers we should see research not only as an intellectual exercise but also as a process of exploration and discovery that is felt deeply'.

Stanley and Wise (1983) acknowledge that emotions and the way they are experienced and manifested are part of the research process. Hochschild (1983) described this as emotional labour. Emotional labour according to her is the management of feelings to create a publicly observable facial and bodily display. The difference between the emotions I experienced and manifested during fieldwork and the emotional labour described by Hochschild is that, Hochschild's emotional labour involves suppression of feelings in order to sustain the outward countenance that produces the proper state of mind in others, in this case the sense of being empathetic and understanding participants' feelings. In nursing however, Hochschild emotional labour is expected to be part of job performance. Unlike Hochschild emotional labour, my emotions in this case were genuine and arose from a deep feeling of sympathy for the participants. Although some qualitative researchers argue against this approach, Oakley (1981) found it very useful when she interviewed women. Bryman (1988) and Bhopal (2010) recognised that the interrelationship of researcher attributes such as race and gender can influence the research process.

My experiences during the data collection process can be described as complex as the impact of a common ethnicity and race and sometimes gender, were experienced both negatively and positively. On a more positive note, some of the African participants assumed that being a black African (insider), I understood some of the black African practices and so they often made references such as '*you know how African men are,..... you know what happens in Africa..*' (as in Chapters 4, 5 and 6). This was a way of acknowledging my insider status by the participants. Other researchers (Phoenix 2001, Bhopal 2009) have also recognised that the effects of similar race (insider status) on the interview process can be complex. Although some potential participants felt uncomfortable with my insider status, some of them took advantage of it (Bhopal 2010), race (Edwards 1990, Egharevba 2001), gender (Rakhit 1998) and age to share some details of their private lives.

3.9 Finding a Safe Space for interviewing

Participants' recruitment and data collection started off well. I was allocated a room for recruiting and interviewing participants and taking field notes at Clinic A. Although this room was used by other staff, it was always available on those days that I attended the clinic for recruitment and interviewing of participants. In order to facilitate openness during interviewing, a safe space in which participants are confident and comfortable telling their story may be necessary. Field and Morse (1996 p. 62) call this 'an ideal situation' because it is not always feasible to have a room to do so. Having a room for recruitment and interviewing is important for the accuracy of data especially as interruption is minimised and participants' privacy assured. However, creating an exclusionary space as such may be intimidating for the participants and is likely to reinforce power differences between the researcher and the participants.

At clinic B, securing a room for interviewing was almost impossible because of the large number of patients that were seen daily and the limited space available at this clinic. While Field and Morse (1985) discourage becoming too friendly with individual members at a research setting, I found that ‘becoming friendly’ was almost unavoidable and worked well for me as it was through this ‘friendliness’ with some team members that I was sometimes sure of a space to interview participants. At Clinic B, I alternated between the seminar room and any clinical rooms that were not in use at the time I needed a room. While I needed to collect data, I was also cautious not to interrupt patient care as our appointments were often scheduled on those days that the participants had appointments at the clinic. At such times the clinics were often busy. Interview appointments were scheduled on these days to avoid participants coming unnecessarily to the hospital. Field and Morse (1996) suggest that data collection should be planned in a way that is less intrusive for the nurse and client.

My initial experience of interviewing at this clinic (Clinic B) was a challenging experience. After identifying a participant, I was invited to see her in one of the clinical rooms. My intention was to discuss with her as usual about the research and for both of us to agree on time and a date for interview if she agreed to participate in the study. The room was quite small but we managed to create space to accommodate the baby’s pram. Field and Morse (1996) note that issues of space are common in research settings. The room had other clinical equipment among which was a standard size sharp’s bin¹⁰ which had just been assembled as it was still empty. As I made my way into the room and not even giving me the opportunity to exchange any form of greetings, in a typical ‘African-centric’ approach (Ochieng 2010), and to introduce myself, the patient looked at me and said “*and you are a black woman. I do not*

¹⁰ Sharp’s bin is a widely available repository used mostly in clinical settings for the safe disposal of used sharps such as needles and blades.

discuss with black people because they are very judgemental". Noticing that I was perplexed, she said '*.....but I will talk to you and it has to be right now*'. Bhopal (2010) notes that the complexities and dilemmas associated with the identity of the researcher and researched can affect the field relationship.

Even though I was shocked and a little discouraged, I tried to maintain my composure, introduced myself and tried to be comfortable. She had a one year old baby in a pram and had perched on the couch as there was no chair in the room. I quickly closed the sharps bin and made it into a little uncomfortable seat on which I was to sit for the next one hour. Without any waste of time I introduced my study and what it involved and handed her an information pack and she said to me '*you can carry on with your interview*'. Oakley (1981) recommends a 'sisterly' relationship in such encounters, and emphasises the importance of maintaining a non-hierarchical relationship in order to gain the patient's cooperation and participation. I had achieved this in previous interviews by telling the participants my 'own stories' which spurred them to open up and tell me their experiences with HIV and AIDS. It was not possible here to tell any story but I ensured that a 'respectful and non-hierarchical' relationship prevailed.

We undertook the informed consent procedure after which I realised I had nowhere to rest my recorder and at the same time the baby was giggling in the pram. During the course of the whole interview, I held onto the recorder and moved it from side to side when she turned her head as she spoke and at the same time I tried to play with the baby who was giggling and wanting to be picked up. The interview lasted only about 45 minutes. Although, Seidman (1998) suggested that interviews should last approximately 90 minutes he also suggests that the duration can vary depending on the age of the participant. This particular interview was interesting as she increasingly became at ease and told me her story. Bhopal (2010) noted that

gender and identity can create a shared understanding between the respondent and the researcher during which a trusting relationship can cause the respondents to open up and discuss their personal experiences.

I visited clinic B as early as possible on those days that I attended for recruitment and interviewing, in order to secure a comfortable space for recruiting and interviewing participants. My strategy was short-lived and I was assigned a little room just large enough to accommodate a little computer table, two chairs and a little trolley. Even though I was allocated this room, on some of the days that I attended the clinic the room was not available. During my first interview in this room with a male participant, I was scared and sat closer to the door. This was a ‘safe space’ in that it was secluded and participant’s confidentiality was assured but how ‘safe was it for me the researcher?

3.10 Managing Social Relations

Researching people with whom I shared similar ethnicity, race and some historical experiences had a huge impact on my field experience. Ochieng’s (2010) work with people of similar race to hers highlighted the difficulties in keeping professional and personal life experiences separate in such instances. Coffey (1999) noted that fieldwork is shaped by personal and professional identities and these identities are shaped by individual experiences while in the field. Some of those who identified with me as a black African after a detailed self-introduction were happy to participate in the study and during interviews were fairly open in telling me their experiences. Bhopal (2009, 2010) recognised that the interrelationship of researcher attribute such as gender and race can influence the research process. While it may appear advantageous, it nevertheless has some intricacies. My

participants were men and women from Africa and the Caribbean and a fairly good relationship was developing between us and this could be assessed by the quality of our interaction which was of a relaxed and friendly nature.

Sarrant – Green (2002) highlighted that members of the black community feel at ease in research about race and racism conducted by someone of similar identity because they share common experiences but they become suspicious of the researcher's motives if the research subject is a sensitive one. Some participants in this study felt uneasy telling their story but did not seem to manifest suspicion but some of them told me intimate things about their lives. Even though self-disclosure is encouraged by many feminist researchers (e.g. Oakley 1981), others (e.g. Walker and Clark 1999) highlighted that this may result in the blurring of boundaries. Many participants did not only identify with me as a black woman but also as a black African and this resulted in an experience of emotional involvement after listening to their stories. This was inevitable as a rapport building process was initiated during their recruitment into the study. This rapport was important in building a research relationship which allowed access into their personal stories (Liamputong and Ezzy 2005, Grbich 2007).

3.11 Dangers in the Field

Doing qualitative research especially that which involves qualitative interviewing might not always be without dangers. These dangers may be compounded if interviewing involves a sensitive area such as interviewing a stigmatised or marginalised group (Renzetti and Lee 1993, Lee 1995, Jamieson 2000, Seal et al 2000, Dickson-Swift 2005). These dangers may be physical, emotional or physiological, ethical and professional.

My study was not without the risk of these dangers, some of which were eminent during the first few months of recruitment and data collection. This was compounded by the eagerness on my part to recruit participants especially as I was an outsider in terms of the patient group as well as the speciality. Some of the sub-groups were very slow to recruit so I was determined not to miss out any patients that satisfied the inclusion criteria and were interested in taking part in the study. I was aware of my ‘insider’ position as a black woman in the context of “black people” in a different cultural setting and anticipated the expected norms to prevail even in a “foreign culture”.

Nevertheless, I was determined to use an ‘African-centric’ type approach described by Ochieng (Ochieng 2010) and the Oakley ‘sisterly’ approach (Oakley 1981) to recruit participants to the study. Whereas Ochieng (2010) describes an ‘African-centric’ approach as one that includes a professional, personalised ethnic approach and respect, Oakley describes a ‘sisterly’ approach which emphasises the importance of building a respectful and non-hierarchical relationship with the participants. While it is clear that our common identity might have influenced the decision to be part of the study to some extent, there were also indications that it was a deterrent. Edwards (1990) noted that black women are more at ease discussing private and intimate details of their lives with someone of a different race than theirs. My assumptions that potential participants would be eager to participate in the study were both naïve and short lived and this was discovered during the recruitment period.

Even though danger was perceived as a farfetched idea, I came close to a ‘risky’ situation. Lee-Treweek and Linkogle (2000 p. 1) highlighted ‘the experience of threat or risk with serious negative consequences’ that could affect the researcher during fieldwork. Some researchers (e.g. Lee 1995, Jamieson 2000, Dickson-Swift 2005) suggested that these risks

have to be dealt with during the phase of data collection. Again in all naivety, I assumed that my insider position was assurance of my safety during fieldwork.

A young potential participant, few months into diagnosis had been referred to me by his treating doctor. Because of a competing appointment, he consented to his phone contact details being given to me so I could contact him later. My first phone call met with an apology for having been unable to meet earlier so an agreement to meet during the next hospital visit in a few weeks was confirmed. From our phone conversation he seemed keen to be part of the study which in a way was quite unusual especially as he had just been diagnosed and was still in the counselling phase of his care. Most of the potential participants in similar circumstances declined to be part of the study. This appointment was missed because of the need to attend to an emergency but another one was confirmed for his next visit in another few weeks.

A phone call on the morning of the appointment as a reminder to me was followed by a request to offer him a lift to the clinic. At this point I was still too naïve to perceive any danger and agreed to pick him up much earlier than his appointment. This was to allow us enough time to go through the consenting process and carry on with the interview before his appointment. I arrived at the address only to find no sign of anyone and attempts to reach him on phone were unsuccessful so I continued to the clinic. Agreeing to pick him up was more of a humanitarian gesture and also because of the relationship that had started to develop between us during the previous weeks than an attempt to try to have him participate in the study.

A later call from my potential participant came reminding me that he was waiting at home and attempts to explain to him what had happened were met with disbelief. My suggestion that he followed me in a cab to the hospital at my expense was rejected in anger. It was at this point that I realised that I had exposed myself to potential danger. My assumptions that potential participants would be eager to participate in the study were both naïve and short lived and were discovered during the recruitment period. However, the potential risk was dealt with in a timely manner.

Emotional danger was there especially at the start of the study listening to personal stories but various opportunities for distraction available to me during data collection provided a source of coping and also attending the clinic twice or thrice a week only, gave me enough time to break away from their emotional stories.

3.12 Data management and storage

Notes were taken during the interviews and completed immediately after each interview (Patton 1990). Each interview was transcribed within 24 hours of recording. There is evidence that such notes are useful in remembering what was said during the interview and it is also important to note participants' facial expressions and gestures as well as the interviewer's reactions and comments. This was discussed and agreed with each of the participants prior to the interviews to prevent any anxieties during the interviewing process. Interviews were conducted by the researcher and at a time agreed with the participant and all interviews took place at the clinics during clinic operating hours.

3.12.1 Analysis

Tapes were transcribed verbatim onto a computer and later analysed manually using thematic analysis and also on the computer using the computer assisted qualitative software (CAQDAS) package MAXqda2. Using both methods was very useful as it ensured that many themes were captured and analysed. Thematic analysis is a process for encoding qualitative data that requires an explicit code which may be a list of themes (Boyatzis 1998). In analysing the data, themes were initially manually identified both at manifest and latent levels, that is, directly observable in the information or underlying the phenomenon and were subsequently generated inductively from the raw data (Boyatzis 1998).

In order to develop themes inductively from the data, the sample was divided into four sub-samples or groups (African men, African women, African-Caribbean men and African-Caribbean women) (Boyatzis 1998). The raw data was further reduced to develop themes which were compared within and across groups. To proceed to identification of themes, data was initially reorganised using the ‘file and block approach’ (Grbich 2007), after dividing the sample into sub-samples. These chunks of data were given labels which constituted themes. For instance, participants’ lack of understanding of HIV, and their desire for more information about it and the inability to differentiate between HIV and AIDS were themed as ‘Knowledge about HIV and AIDS’. This was aimed at reducing the data to meaningful groupings which would be easier to manage (Grbich 2007) though still keeping chunks of data together. This study contained a comparative element so organising the data this way made it easier for common themes to be identified and for any apparent differences between the groups and gender to be easily teased out.

The computer assisted qualitative data analysis software (CAQDAS) package MAXqda 2 was also used although initial analysis was manually done. Manually analysing data may seem to be time consuming but it has an advantage that it enables further familiarity with the data (McLafferty and Farley 2006). Insufficient understanding of the MAXqda 2 software in the beginning meant that initial analysis was done manually. McLafferty and Farley (2006) highlighted the difficulties associated with mastering qualitative analysis software. Choosing this particular software package was not because of familiarity with it, but simply because of its popularity among peers. This was not in line with Miles and Huberman (1984) who have suggested that the choice of a particular qualitative software package should be based on the individual's knowledge and understanding of it. Although learning to use this package was time consuming it enabled further immersion in the data.

The MAXqda 2 software package was useful because it enabled easy navigation across the files or data thus enabling closeness to the data. The ability to switch from one data file to the next, which is not possible with manual analysis of data, or to navigate through the data facilitated the within and between comparison of sub-groups (Burnard 1994) and was an added advantage. This made comparison of trends and patterns within and across subgroups easier and more interesting (DeNardo and Levers 2003) than manual navigation of data. In addition to this function the ability to retrieve coded segments of data also helped in assessing similarities and differences in the themes across the subgroups. MAXqda 2 also allowed data to be coded in different ways including colour coding and coding chunks of data. This was similar to the manual file and block approach described above. These together with the ability to generate outputs that can be viewed in word are not only less time consuming but also efficient.

3.12.2 Trustworthiness

The trustworthiness of qualitative research has often been questioned especially by positivists (Shenton and Hayter 2004). This is based on the differences in methodological approaches between qualitative and quantitative research studies. Streubert-Speziale (2007: 49) pointed out that

'the goal of rigour in qualitative research is to accurately represent study participant experiences'.

Jeanfreau and Jack (2010) suggested that any research study should have rigour or scientific strength although different criteria should be used to determine the strength of rigour in qualitative and quantitative studies. Many qualitative researchers (e.g. Lincoln and Guba 1985, Silverman 1984, Seale and Silverman 1997) have however responded to the challenge by suggesting strategies for ensuring the trustworthiness of qualitative studies. While Silverman (1984) and Seale and Silverman (1997) talk about 'count of events' or 'quasi-statistics', Lincoln and Guba (1985) have developed four criteria to evaluate the trustworthiness of qualitative research studies. Their criteria include:

Credibility – confidence in the truth of the data.

Dependability – data stability over time and over conditions

Confirmability – objectivity or neutrality of data

Transferability – extent to which findings from the data can be transferred to other groups or settings

In this study, steps to ensure rigour of the whole process were followed using the four criteria for establishing the trustworthiness of qualitative studies suggested by Lincoln and Guba outlined above as well as the ‘count of events or ‘quasi statistics’ proposed by Seale and Silverman (1997). These are discussed in the following paragraphs.

Methods used to strengthen data *credibility* in this study included audio recording of interviews which were later transcribed verbatim. One of the ways suggested by Yin (1994) to ensure the credibility of a qualitative study is the use of valid research methods and robust data analysis techniques. Data were collected for this study by the interview method using an approved interview guide to ensure that participants answered similar questions and the thematic approach was used to analyse the data both manually and by using the CAQDAS specifically MAXqda 2.

Shenton and Hayter (2004) pointed out that holding frequent meetings with the research supervisor is one of the ways to ensure the credibility of a research study. He asserted that such meetings provide a forum for debriefing and also provide an opportunity to highlight any flaws on the course of action taken by the researcher. Regular meetings that provided a forum for debriefing took place between my research supervisors and myself during which we discussed any issues of concern. Some of the transcripts were seen by them during some of these meetings to validate the data and any issues or potential issues were discussed and resolved.

Dervin (1976) talked about institutional triangulation which involves getting a variety of perspectives about a research subject from diverse settings in order to have a better view of reality based on a wide range of individuals. She suggested that it is important to recruit

participants from different organisations to reduce the effects of any local factors that may be peculiar with one environment. Participants for this study were recruited and interviewed at two different clinics in two different hospitals. These two sites had different characteristics and were independent of each other. Field notes were also taken and participants were adequately described.

Some researchers (e.g. Patton 1990, Jeanfreau and Jack 2010) have suggested that in order to ensure research credibility, the researcher should report any personal and professional information that may have affected data collection, analysis and interpretation negatively or positively. To do this I have defined my position in the research and have been reflexive in describing the methodology. As a black African woman interviewing black African and African-Caribbean people, I was aware that it would be possible for data collection to be influenced both by my own emotions and by the participants perceptions of me and our common identities, therefore, I remained aware of this potential at all points throughout the research process.

Some researchers (e.g. Sandelowski 1986, Polit et al 2006, McBrien 2008) have suggested that the credibility of a qualitative research study can be evaluated by member checking. This approach was not appropriate for this particular study given its sensitive nature and the difficulty arranging meetings with participants.

Dependability was assured by organising the participants into four sub-groups (African men, African women, African-Caribbean men, African-Caribbean women (Boyatzis 1998) and then using the block and file approach (Grbich 2007) to organise the data in an easy format to be able to tease out the themes at the same time comparing them across and within

subgroups. Maxqda2 software was also used with similar organisation of data and provided an easy way of navigating across and within groups and sub groups. Shenton and Hayter (2004) pointed out that the dependability of a research project can be assured by describing the research design and its implementation as well as giving details of data collection and what was done in the field. These have all been detailed out in this chapter.

To ensure *confirmability*, the transcripts and field notes have been kept to enable an independent auditor to be able to come to conclusions about the data. Jeanfreau and Jack (2010) also suggest being reflexive in the account of the research so as to be able to know how the researcher thoughts and values influenced the research process. The methodology has also been detailed out (Shenton and Hayter 2004) using a reflexive approach.

Guba (1981) pointed out that *transferability* can be assured by providing a detailed description of the research setting as well as the transactions and processes observed and encountered during the study. Guba (1981) asserted that what the researcher may consider as unimportant may be important to the readers. Details of the characteristics and the number of participants that took part in the study have also been presented, the length of time that data collection took and the data collection method employed have been fully described.

Rigour and validity were also enhanced by supporting generalisation within the sample by counts of events in the analysis of data. Silverman (1984) called this count of events in qualitative research ‘quasi-statistics’. Seale and Silverman (1997) suggested that such counts can address concerns in reporting qualitative data for example concerns that undue attention has been paid to rare events at the expense of more common ones. The inclusion of numerical

data in qualitative research has also been supported by Miles and Huberman (1984), Bryman (1988), Hammersley (1992) and Erickson (2007).

3.13 Summary

This chapter examined the research journey using a reflexive approach as a way of maintaining rigour. It described the process of gaining access to the study subjects and of recruiting and interviewing them. It also described the challenges that were encountered during the process such as finding a safe space for interviewing participants, dealing with potential dangers in the field such as physical dangers and dealing with issues of social relationships such as identity issues. This chapter also provided insights into how data was managed and concludes by stating how rigour was maintained throughout the process.

3.14 Conclusion

Conducting qualitative research on participants with whom the researcher share similar identity and ethnicity can be very complex. While it might be advantageous in some instances, in others, a similar identity may constitute a barrier to conducting a good interview and this becomes even more complicated when dealing with a sensitive subject area such as HIV and AIDS. A hospital setting as the place for interviewing study participants can potentially affect their responses. Interviewing participants for the current study made me ponder on whether their responses would have been different if they were interviewed elsewhere other than the hospital and also if they were interviewed by a non-health professional. There are often potential dangers when doing field research and they may be compounded when researching sensitive areas. It is therefore necessary for the researcher to

think this through at the outset in order to be aware of these dangers so as to find ways of preventing or addressing them if they do arise. Finding a safe space for interviewing in field research is a crucial problem. It is important to get a safe space if interviews are to be conducted properly. A safe space ensures that field notes are taken and that participants are comfortable to be able to tell their stories.

This study sets out to investigate the help-seeking behaviours to diagnose HIV and AIDS among UK based black African and African-Caribbean people, and to investigate heterogeneity if any, in those behaviours by place of origin (Africa vs. African-Caribbean) and gender. The next chapter, Chapter Four, presents the first chapter of the analysis which gives an overview of participants' perceptions of HIV and AIDS and shows how this affected help-seeking for diagnosis. Because of the sensitive nature of the subject and because of the need to maintain confidentiality, the following abbreviations with their full meanings have been used throughout the analysis chapters.

AM – African male

AW – African woman

CM- African-Caribbean male

CW-African-Caribbean female

Chapter Four

Perceptions of HIV and AIDS

4.1 Introduction

HIV and AIDS are names that are mentioned almost every day. Although these names may invoke some fear, many people appear to have very little understanding of them and furthermore, even fewer people can differentiate between HIV and AIDS. The current chapter analyses participants' perceptions of HIV and AIDS in the context of this study. Knowledge and knowledge gaps about HIV and AIDS are highlighted showing how these have the potential to affect participants' desire to seek health care.

4.2 Knowledge of HIV and AIDS

4.2.1 Participants' Knowledge of Causation and Modes of Transmission of HIV and AIDS

Knowledge about HIV and AIDS varied amongst participants in the study. For instance, some participants described their understanding of HIV and AIDS partly in terms of perceived gaps in HIV and AIDS knowledge in general. Information about HIV and AIDS among participants generally appeared incomplete, however many of them understood HIV and AIDS from various perspectives described below.

Eight of the participants in the study from either black African or African-Caribbean backgrounds perceived HIV and AIDS as an illness caused by a virus and transmitted through unprotected sexual intercourse but offered more hesitant accounts that referred to incomplete knowledge of HIV and AIDS.

I'm know that HIV is a, is a disease but we get it from the, the sexual...something like that. The most thing people, me, me I'm know that people still don't understand the thing so they still have to do advertising (Transcript 8 AM¹¹).

Participants who perceived HIV and AIDS as an STD showed greater understanding of the modes of its transmission. This perception was more common among men than women and among African-Caribbean participants than black Africans in the study. This was evident from their awareness of the way they had acquired their infection.

Sadly a year and a half ago I met this person, who I fell madly in love with and we had unprotected sex, we both decided to have unprotected sex and this is the thing, I didn't realise she was carrying the virus (Transcript 14 CM¹²).

The African-Caribbean participants' understanding that HIV and AIDS is an STD also reflected in their help-seeking patterns (Chapter 6). An analysis of the help-seeking pathways of participants in the study indicated that more African-Caribbean men went for voluntary testing than did the rest of the participants in the sub-groups but overall, voluntary testing was not generally common among both groups studied.

¹¹ For the purpose of anonymity, AM refers to African male.

¹² CM refers to 'Caribbean male.'

The perception of HIV and AIDS as an STD among African-Caribbean men also influenced their practice of safer sex evident in their tendency to use the condom and the practice of regular screening by some, a practice that was not noticed among black African men.

4.2.2 Knowledge of the Relationship between HIV and AIDS

All participants in the study, black African men and women and African-Caribbean men and women expressed a lack of understanding, of the difference between HIV and AIDS. Prior to their diagnosis they associated HIV and AIDS with death.

But people are still very negative about HIV; they think you are promiscuous....

People out there, once they hear you have HIV, they just think you are dying, they think it's AIDS. I used to think like that until my consultant told me HIV is different from AIDS. Now I know the difference. Our fellow black people have to be educated; they have to be aware...We need education amongst ourselves to change our perception of HIV and victims; that education, people need to be aware, to be aware that HIV is not AIDS (Transcript 24 AM).

Many of the participants expressed the need for more education and information about HIV and AIDS and highlighted that their perception of HIV as AIDS was understood as dying. This perception tended to negatively influence help-seeking for diagnosis in that they no longer found help-seeking useful. Although this attitude could be explained in term of gaps in knowledge, it essentially appeared to be a reflection of fear consistent with literature and such participants could be described as experiencing feelings similar to the feeling of biographical abruption described by Locock et al (2009) in their study with people suffering with motor neurone disease (MND) described in the literature.

4.2.3 Access to Information on HIV and AIDS

All participants acknowledged having received information about HIV and AIDS from the clinic but stated that such information was insufficient and incomplete. They felt the need for more detailed information to fully understand the disease.

I think, well there are various factors, one...er the other thing is like.....

Individuals er, it is the knowledge of what HIV is. I think the information is not complete. They talk of HIV but they don't explain it fully. Some people, they don't comprehend what HIV is and what's AIDS. That's the thing. Those many people may think of AIDS when there is HIV (Transcript 27 AM).

Some of the participants expressed their tendency to avoid learning more about HIV and AIDS and confirmed that such a tendency was higher especially during the period prior to being diagnosed.

I remember those days, you know, when you even hear, even when there is an advert on it [HIV and AIDS], I just turn my television off, you know; you don't want to hear, you don't want to, so.... (Transcript 3, AW¹³).

This was a possible outward manifestation of fear. It is possible that while such a tendency may still persist after diagnosis leaving some of the participants with only basic understanding of HIV and AIDS, some of them may find it necessary to know more about the illness.

¹³ AW in this document refers to 'African woman'.

4.2.4 Information Sources and Support for diversity of language

Providing health education and information are some of the strategies to encourage help-seeking for HIV diagnosis. All participants in the study acknowledged receipt of information about HIV and AIDS at the clinic both in the form of leaflets and verbally. The use of information leaflets supplied to patients provided a good medium for education and information about HIV and AIDS but did not appear appropriate in all circumstances as expressed by some of the participants. Apparently this is a very valid education method but it could potentially be ineffective as participants highlighted the high risk of unintended disclosure of their HIV or AIDS status to family or friends posed by leaflets being taken home. As such many participants avoided this source of information.

Yes I was given leaflets which I destroyed, erm...reason being I've got friends coming in and out. I don't want anybody picking it up by mistake or picking any information that will say or that will indicate what I'm going through, you know!, that's my reason (Transcript 3 AW).

Although avoiding information leaflets may prevent unintended disclosure of their HIV status, some of the participants remained insufficiently informed as they tended to depend only on the verbal information that was provided them at the clinic. Some of the participants in the study could speak the English language but could not read or write in the English language meanwhile most of the leaflets were in the English language. Some of the participants suggested that information giving strategies should be made appropriate to the needs of the different groups of people that attended the clinic.

If you have 30 people coming here, 30 young people coming here, you are not going into schools, so, so, and so. The mere fact, underlining fact is that they have a treatment; they have contracted a sexual disease so they need to, you know, whether someone has told them about the effects when they are here. Giving them leaflets and explaining to them why they contracted so, and so, so, doesn't help them; it cannot help them because they cannot read (Transcript 9, CM).

Some of the participants especially black African women appreciated the use of picture messages as a valid strategy to provide information about HIV and AIDS but noted the absence of such a strategy at the clinic. The use of such a strategy was highlighted by them as important especially among illiterate groups.

Picture messages, very useful! They lack picture messages here! I have got loads of written information but not even one picture message. Again picture messages are good for people that come here that cannot read or write. Back home [In Africa], when you get into the health centre, what do you see [...] especially when it comes to seeing a picture of a mother holding a baby suckling; what comes to the mind? Nothing is said but you know straight away what they mean; encouraging breast feeding. Here most people think that it's the first world experiences (Transcript 5, AW).

Some of the participants did not have English as their first language and picture messages could be a good information and educational method for the groups studied. Moreover the use of picture messages appeared to be a familiar teaching method to black African participants who expressed that this method is used regularly in Africa. Such participants

advocated picture messages displayed at the clinic as they would learn from these messages without necessarily taking them home.

Mapara (1989, 1990, and 1992), a physician, found this method very useful when he used it to raise awareness of HIV and AIDS both in Africa and the UK. He reports this method very effective as a health education method in HIV education. This method was also found very useful by the researcher during workshops organised to raise awareness of HIV and AIDS among young people of African and African-Caribbean backgrounds in Brent London in 2010. Some of the participants especially those from Africa who were familiar with this method of information and education highlighted its usefulness in HIV and AIDS education. However they did not report on the use or the effectiveness of this method of health education post HIV diagnosis.

A number of participants highlighted the low priority given to HIV awareness campaigns in the UK evident in the apparent absence of HIV related messages on the UK media. They emphasised that HIV and AIDS which are incurable diseases should have media priority over other STIs such as Chlamydia that currently seem to be have priority on the STI prevention agenda in the UK.

The media in this country, to be frank with you, when it comes to AIDS and HIV, they are not giving as much publicity. There is no enough information. It is now only of late when they are talking of STIs and Chlamydia but they are not actually mentioning HIV which is the biggest threat because STI, well is treatable but HIV, they must put HIV on top [prioritise] and STI at the bottom, because we are talking of a situation, if somebody has got maybe most likely have got HIV which is the

most dangerous disease. Information on AIDS is not much, there is, there is not much information you know, whether on the television, even in the papers. It was there sometimes, maybe in the early 90s when the disease started but at the moment, ah! there isn't much information on AIDS (Transcript 27, AM).

Although the media (television, radio, newspapers and magazines) is a good medium to reach out to many people with information about HIV and AIDS, it either appeared not to be used regularly for such a purpose or it was used as noted by some participants, for non-health related issues such as advertisements and celebrity gossips. Some participants stated that even when used to provide health information; low priority was accorded to HIV and AIDS with Chlamydia receiving more attention even though it is a treatable STI. However, the use of social networking sites such as twitter, face book to deliver health education messages about HIV is growing in America especially with CDC but it is not very much used in the UK. Fox (2011) suggested that online health information is driven by the availability of social media tools and the increased desire and activity of people living with chronic conditions to connect with each other. Nowadays such messages about HIV and AIDS seem to be limited to World AIDS Day which may leave those who need these messages most, insufficiently informed about HIV and AIDS. Such concerns were common among men and women from both Africa and the Caribbean.

Another participant highlighted that if HIV and AIDS related messages did feature on the media, they were often written in small print in a few lines while less useful information occupied the headlines.

Important health messages on the newspaper are written in very small print and occupy a very tiny corner but you find less important messages like celebrities pictures doing stupid things or news occupying the headlines (Transcript 5, AW).

The absence of programmes on the media to raise awareness of HIV and AIDS may impact negatively on the younger generations' ability to be informed about HIV and AIDS especially black Africans and African-Caribbean people in which the incidence of HIV and AIDS is steadily increasing.

4.3 Participants' Perceptions of HIV and AIDS

4.3.1 Participants' Perceptions of their Sources of HIV and AIDS

Infection

Some participants still had the misconception that HIV could be contracted by other routes other than the three well known routes of transmission described in chapter two. For instance, some of the participants still expressed uncertainties about how they contracted the disease with the suggestion that their infection could have been acquired by other routes such as kissing an HIV infected partner.

If I've got it [HIV], it could be by a mistake somewhere or maybe I have kissed somebody who has got that HIV, who has caused that, that thing, but, but for the doctor to actually explain it to me properly, it means that I've got it in about 2 – 3 years back, but I think my immune system was strong, fighting and fighting it until it was getting worse; (Transcript 21 CM).

Some of them noted that their partners reported having got infected by sharing a towel with an HIV infected person and by using a shared toilet. For example the following participant's husband linked his source of infection to toilet seat or to sharing a towel.

He [my husband] will still be in denial, he will not say to you well, I've been with somebody, he would say to you oh I don't know, somebody used my towel, I said I'd love to see how they managed to get their towel and wrap it around your private part and da da da da (giggles) you know, I'm telling you this it's silly, it's silly (laughing) but this, you know, so [...] when I've had infection and I said look you've given it to me, he [her husband] said oh I've caught it on the toilet seat, and I said to him look don't be so silly, you cannot catch things on toilet seat 'cos when the air that takes it, is going to destroy the bacteria whatever, so he thinks I'm stupid (Transcript 15, CW¹⁴).

There is still some ambiguity as to whether HIV may be contracted through any of these ways especially through kissing which involves some bodily fluid contact. None of these methods has been documented as a possible route of HIV and AIDS transmission as presented in the literature. The suggestion by participants of contracting their illness by other routes other than the well-known ones appeared to reflect the need to offer a different account of their sources of infection.

¹⁴ CW in the document refers to 'African-Caribbean woman'.

4.3.2 Perceptions of HIV and AIDS as ‘Africanness’¹⁵

Eight of the participants in the study perceived HIV and AIDS as an ‘African thing’ which to them was part of ‘Africanness’. This perception appeared to be influenced by the number of African people that were treated for HIV and AIDS and the number that had died from HIV and AIDS related illnesses as portrayed both by the media and the general public. Some other participants used ‘African way’ to portray ‘Africanness’. They also used ‘African way’ or ‘African thing’ in a wider context to refer to other attitudes and behaviours common among black Africans that were considered risk factors for HIV and AIDS or as HIV and AIDS itself. This perception was common among participants from both backgrounds. These are all further discussed in detail in Chapter 5.

4.3.3 Perceptions of HIV and AIDS as an outcome of Prostitution

HIV and AIDS were still understood by many in terms of prostitution. For instance, eleven of the participants in the study perceived HIV and AIDS as an outcome of prostitution.

I have never been a prostitute. I'm not a prostitute; Even prostitutes because, no one knows why they're doing what they are doing, I can't judge anybody but only if Africans will remove the element of judgement and realize that we're all going to die anyway, somehow because we're all going to die of something, ok, so and, be a bit more pragmatic in the sense that, and I was like that because I'm one of those people
(Transcript 11, AW).

¹⁵‘Africanness’ is a term used in this study to embody everything referred to as African and includes behaviour, attitudes and attributes.

One of the ways by which the public perceives prostitutes is that they are people who degrade themselves by having sex in exchange for money. Early studies have shown a high rate of HIV and AIDS infections among prostitutes suggesting that they are probably more engaged in risky sexual activities than non-prostitutes. It is also well known and documented that prostitution has played a great part in sustaining the HIV and AIDS epidemic evident in significantly higher rates of HIV infection among prostitutes and their clients as compared to other populations. However, the true extent of HIV transmission from prostitutes and their clients to other populations remains generally unknown (UNAIDS 2009).

As soon as they say you are [HIV] positive, they say probably, she must have been prostituting herself but of course, even married women, or you just sleep with somebody. Anybody who says, oh! I can never get it!, is just a joker because, then, being married is not, is not, you know, is not security for you and, or if you've never been touched by a man it's not security.. (Transcript 3, AW).

Some of the participants suggested that such public perception of HIV and AIDS as a disease of prostitutes was a reflection of the lack of information about or a lack of public understanding of HIV and AIDS.

We also feel that it is a shame for people who think we are prostitutes because of the public not because of what you do which is normal, but it is because of the eyes of others (Transcript 2 AW).

Some of the participants in the study were unmarried but most of them were married or were in a long term relationship. Some of the unmarried participants had regular partners. Some of the participants were aware that HIV was not only transmitted sexually and could be contracted through other routes suggesting some awareness of its various modes of transmission among some of the participants.

Some of them, most of them, but I think back in Africa, yes, it's like you haven't...done It [had sex]... but everybody does that [has sex] everyday but when you contract HIV, everyone says, ah, he is a womaniser, you see, this and that, de, de de erm, you know, no respect [...] Tell them, this is the study, anything can happen to anybody, it is not only through sexual intercourse and it is not spread by you looking after sick people, they have not put it into their heads....(Transcript 2, AW).

Some participants highlighted the public tendency of stereotyping people once they get infected. Although many people are involved in sexual activity, they are not seen as prostitutes but are labelled prostitutes when they get a positive HIV diagnosis. However, the frequency of exposure to HIV and AIDS infections may not be the only determining factor for acquiring HIV and AIDS infection as people have reported being infected with the HIV virus from a single exposure and some have reported not being infected after long term exposure. For instance, the partners of some participants in the study remained uninfected despite having had unprotected sex with their partners for a very long time.

Well two of my partners, I know they are negative because it was not because of my diagnosis, we were just conversing and it came up that we would go to the doctor for

test – eh and what they'd done is that they were tested and they were negative. There was two of them (Transcript 25, CW).

I told my boyfriend because we were living together for 2 years in the same house and I told him to go and do his test to see if he's got as well. He went, he is still doing the test and he is still negative (Transcript 16 AW).

Few participants in the study indicated regular use of condoms but others indicated the difficulty in using the condom in long term relationships. This is consistent with some literature. For example, Meeker and Klein (2002) study showed that the practice of safer sex tends to reduce with permanent or long term relationships as mutual trust develops among the partners. Also, gender inequalities among black Africans indicate that women are unable to suggest the need to use a condom.

You are a bad person [HIV infected person]. I don't know because where I come from; you are somebody who jumps from men to men. Where I come from, that's what they think about (blushes), as for me I got only one partner and he knows it and I have still got it so I don't believe in like jumping from one person to another because somebody can jump from man to man but the person will still not have it (Transcript 19, AW).

The quote above suggests a strong association of STIs with ideas about sexual immorality and this makes them particularly stigmatising (Ahmad and Bradby 2008). As such people will potentially feel reluctant to test or fail to disclose their status for fear of the judgemental tendencies of the public.

4.3.4 Perception of HIV and AIDS as an Outcome of Carelessness

HIV was also perceived as an outcome of carelessness. Three of the male participants from the African-Caribbean group perceived HIV and AIDS as an outcome of carelessness. Black African male participants did not express similar views. Most of them were either married or were in steady long term relationships. Most of the African-Caribbean men in the study were either divorced or unmarried and steady long term relationships were not common among them. Even though they did not have such relationships, safe sex was not regularly practised by some of the participants.

I think if I was doing the right way going [having safe sex], having safe sex, having sex with condom, this, then this [HIV infection] wouldn't happen. When you don't use protection, you are likely to have any sickness, ..err, anything can be happen to you so you have to be erm. careful...Eh..r, from my point of view with the sickness, I said if I didn't walk that pathway with carelessness I wouldn't have this [HIV infection]. If I did go and protect myself, er...m, so all things, I don't blame nobody, I blame myself (Transcript 1, CM).

There was a tendency of low risk perception among some of the participants that resulted in unsafe sex practices. For instance, one of the participants usually had unprotected sex because her partner group was married men whom she associated with low risk of HIV and AIDS infections. This is consistent with Burns et al (2007) findings in the literature of low risk perception among black Africans.

They were all married men and I did not really think that they could have any type of illness like that. I did not really think that I was at risk at all (Transcript 25, CW).

Carelessness can be associated with low risk perception (Morris et al 1996), unrealistic optimism that it is unlikely that they will be infected and perhaps the dislike of condoms use as stated in the literature.

Some of the participants associated their failure to use the condom with the desire to feel the naturalness of the sexual encounter. Failure to use the condom is not only associated with low risk perception but also with the desire to feel the naturalness of the sexual encounter as well as to symbolise romantic involvement as stated in the literature.

To be honest, I did not think about the condom. You know I do not even like the condom and most men don't like it too (Transcript 25, CW).

Some participants did not seem to realise the importance of using the condom to reduce the spread of HIV infection. The perception of a sexual encounter seemed to be centred on the need to have pleasure and not the need to remain uninfected. The dislike of condom use was common among both black African and African-Caribbean participants and among men as well as women. Some participants perceived being infected with HIV and AIDS as a distant possibility.

I always think that it will never be me [to have HIV infection]; it will never catch up with me because I don't go with prostitutes; I don't sleep with any girl who only talks to me. Sometimes we only kiss and that's it; and she go her way, and I go on my

way. Even with condoms, I don't even want to use them. Because I don't like condoms, I don't want sex at all (Transcript 21, CM).

The optimism that HIV and AIDS were for someone else could probably be blamed on low risk perception and the need to understand the risks involved in unsafe sexual practices. This perception was in line with the general public tendency that people see things happening to others and not to themselves.

4.3.5 Perception of HIV and AIDS as a Death Sentence

HIV and AIDS were also associated with death, for example, nine of the participants in the study, both men and women from Africa and the Caribbean perceived HIV and AIDS as a death sentence.

That I'm now a danger to other people, you know what I mean. I just felt you know, getting involved with anybody now is like a death warrant, you know. I've got somebody else's death warrant [infecting someone], and I say if it's death, that it is just me, that's fine, me, you know, but the potentiality of infecting somebody else, you know; that really got me (Transcript 3 AW).

The portrayal of HIV and AIDS as a deadly disease dates back to the 1980s as evident from the frightening nature of HIV and AIDS awareness campaigns. It is understood that in the early days of the epidemic, health education campaigns used the symbol of a tombstone in the UK to raise awareness and encourage control of its spread. This seems to have made most participants to internalise this perception of HIV as a death sentence. Moreover, the idea that there is no cure for HIV and AIDS and the high number of deaths resulting from HIV and

AIDS infections may be the influence on the perception of HIV and AIDS as a death sentence.

Although there have been advances in HIV and AIDS research that have transformed HIV and AIDS from a terminal illness to a chronic disease, participants' views still reflected some scepticism about HIV being a chronic disease. Black African cultures and beliefs around HIV and AIDS and illness in general compounded by the use of alternative medicine suggest that HIV and AIDS are not given sufficient attention by the patient in terms of seeking medical attention. This practice is unlikely to encourage black Africans and African-Caribbean people to change their perception of HIV or AIDS as a death sentence to a chronic illness.

I passed out [on hearing my diagnosis]; I was shattered. I felt like a dead sentence had been passed; I could not remember the bus number to take me home. I was very upset for being infected because of no fault of mine. There's really nothing that comes to your mind and it's death. It's like a death sentence passed on you (Transcript 5AW).

Although treatment for HIV infection is currently available, there still appears to be doubts as to its effectiveness among some participants such as the one quoted above. This may also suggests the need for clear information and education both to people affected by HIV as well as those that have not been affected.

4.3.6 HIV and AIDS as a Chronic Illness

Only four of the participants in the study appeared to have more information and greater understanding of HIV and AIDS. Such were those who perceived HIV and AIDS as a chronic illness. They appeared more relaxed about their illness and likened it to chronic illnesses like

diabetes and hypertension. Their understanding of HIV as a chronic illness appeared to help them in their help-seeking and in their ability to cope with HIV.

The mentality is still there [death sentence] so we need to clear that mentality of the Africans that the sickness [HIV and AIDS] when you have it, it's just like somebody having a diabetic, being a diabetic, having cancer, it is the same. It's a chronic disease that we all have but that mentality needs to be cleared from their minds on national TV or something; maybe some TV.... The people I have come across, few, the Whites erm, do understand the sickness more than black people I have come across with [with HIV] (Transcript 19, AW).

Some of the participants stated that HIV and AIDS was better understood by the white population than the black populations especially black Africans. Although some of the participants in the study neither perceived it as a death sentence nor as a chronic illness, they expressed a preference for HIV and AIDS to diseases like cancer. Comparing with cancer, some of the participants preferred HIV and AIDS and highlighted the absence of pain in HIV and AIDS.

It [HIV and AIDS] is not a death sentence. It's probably not as bad as cancer because with cancer you are in pain but with this [HIV and AIDS]; it is quite containable If you are diagnosed early. I felt quite positive that... I brought it to the open; I literally caught it in the first stage... (Transcript 14, CM).

HIV and AIDS were also perceived as a containable disease with early diagnosis. Some of the participants preferred HIV and AIDS to other chronic diseases like hepatitis or diabetes

because HIV and AIDS would not impose on them the restrictions that are imposed by other chronic diseases such as diet restrictions with diabetes. With good follow-up and management, patients with HIV and AIDS have a better life than those suffering with diabetes.

... if they put HIV, hepatitis, diabetes all these things or let's say cancer, I say If you are wise take HIV (laughs) and some people look at me like mad person, I say no, why I am telling you that now, HIV does not kill you, except you kill yourself but hepatitis can kill you. I have seen my friends that they have such kind of things [hepatitis, diabetes] it does not take up to one week they discover it [hepatitis, diabetes] and they die because it has not been discover in time [...] cancer the same thing, cancer they will give you time you are dying in so so weeks, HIV if you are taking your medication you can eat anything, diabetes will not eat what I want to eat
(Transcript 12, AM).

These preferences were related to the almost predictable outcome of HIV and AIDS unlike cancer which they thought was a terminal problem with an unpredictable outcome or diabetes with diet restrictions. The understanding that people with HIV and AIDS can live a normal and longer life on medication can serve as an incentive to people to seek help for diagnosis and consequently treatment. For instance, it appeared that after diagnosis, a greater understanding of HIV and AIDS and the difference between HIV and AIDS changed some participants' perceptions of HIV and AIDS as a death sentence to the understanding of HIV and AIDS as a containable disease.

Because they are afraid of what that means for them with regards to a death sentence, and, and also being a part of that er..a group of individuals who are positive [for HIV]

which is not a pleasant thing to be proud of, the stigma that comes with that..... I thought it was a death sentence. However, my opinion has changed now. When I speak to friends who are not positive now, they are aware of the dangers around HIV and they test regularly and that is something I wasn't doing but then I didn't have reason for that because I was having safe sex at all, at all times (Transcript 22 CM).

The perception of HIV as a death sentence and the unpleasant feeling associated with being HIV positive were potential contributions to the failure to test. The scepticism about testing as is evident in the above quote appeared to relate to the understanding of HIV and AIDS as a death sentence and to the stigma (felt and/or enacted) that comes along with knowledge of a positive diagnosis.

4.3.7 Perception of HIV and AIDS as Leprosy

Three black African women in the study, perceived HIV and AIDS in terms of 'leprosy', 'death sentence' and 'curse' and indicated that they had suffered rejection and segregation, an experience that was similar to that of leprosy patients.

... (Laughs) judgement! Because if er, you know, it could be equated to say leprosy in a way because in those days you feel you don't go near leprosy person so you're ostracised, segregated. Probably, there is no physical you feel... separation and that also hurts. (Transcript 3, AW).

The use of such terms by participants to provide an understanding of their experiences with HIV and AIDS has the potential to increase stigma and discrimination (Aggleton et al, 2005, Ogden et al, 2005) towards HIV and AIDS patients and this potentially has a negative impact

on people's decision to seek help for diagnosis even when faced with symptoms. It is likely that HIV and AIDS patients identify with leprosy patients (Barrett 2005, Hagens 2007) because of the stigma it engenders. Tsutsumi et al (2007) described leprosy as a highly contagious disease caused by a bacterium known as the *Mycobacterium leprae* that affects the skin, mucous membranes, and nerves, causing discolouration and lumps on the skin and, in severe cases, disfigurement and deformities. It is the physical deformities resulting from the illness that give rise to the stigmatising identity – 'leper' (Tsutsumi et al 2007). Harris (2011) suggested that the leper identity is used as a metaphor for degradation in everyday life especially for stigmatising illnesses.

While the cause of stigma in lepers is likely to be related to the physical deformities that result from their infection, and the negative perception of society of these deformities, the cause of stigma in HIV and AIDS appears to be the mode of transmission, especially the sexual route which gives rise to the notion of promiscuity and prostitution. Promiscuity and prostitution are negative connotations and therefore many people may not want to be identified with promiscuity or prostitution. It is possible that HIV patients identify with leprosy patients because of the similarity in their experiences from the attitudes, responses and behaviour of society towards them (Van Brakel 2006).

... You do a urine test and they put a huge tag on it that 'danger of infection'. That's my urine so why would you put that if it is not? It is almost like leprosy, because leprosy is highly contagious whatever [...] I don't have leprosy, I am just going on but even though at the back of my mind I'm thinking, yes I have leprosy, it is the same (laughs) (Transcript 11, AW).

This perception was common among black African women than all other participants in the study. HIV and AIDS and leprosy are both highly stigmatised public health problems especially as they both give rise to the ‘spoilt identity’ described by Goffman (1963). Like leprosy, most people diagnosed with HIV and AIDS conceal their illness. Attending a health care facility for diagnosis is likely to pose a threat to confidentiality which is an issue that was clearly stated by participants in the study.

....when the doctor then referred back to my GP on what I was having for my stomach complaint, wrote there that I am HIV known. I never told my GP that [my diagnosis]; and my GP then contacted me and arranged a meeting. At the meeting he told me ‘I have been made aware from the hospital, [St Michael’s – anonymous], that following your stomach exams, you are HIV positive’. That was another conversation I did not expect to have with my GP and again it all came through this clinic as a result of me giving my name to this clinic and you know, for some reasons other than the jobs I do for example, if people apply for work or mortgages, they ask me about my medical history and they may say, ‘can we write to your GP?’. Now they will always have that information available as the GP cannot ignore it. It is on my file! (Transcript 22, CM).

The threat to confidentiality can be a big deterrent to seeking help for HIV diagnosis. The ability to conceal an HIV positive status potentially provides a source of coping. The dependence on a negative HIV status for the success of some processes in society, for example, acquiring a mortgage and health insurance, suggests that people would not want to disclose their positive status to their GP in order to be eligible for such processes.

4.3.8 Perception of HIV and AIDS as a Curse and Punishment

Five of the participants perceived HIV and AIDS as a curse and some as punishment for sins against God.

I don't know, erm I've never had the experience [sexual relationship] with anybody else to just say well I could have got it from Tom, I could have got it from Dick or Harry, so it's very, very hard for me to think you know I've got this curse [HIV], I call it the curse. There's nothing else (laughs), there's no other way, I call it a curse. I felt I had the plague, first thing I said to the doctor 'how long have I got to live, so that I can sort out my children and everything else (laughs) and he sort of looked at me thinking what's wrong with this woman! It's a disease but they don't ..er they think it is a curse. People, generally, they look at HIV the same, same as AIDS. They don't seem to know the difference so it's like you're marked and people's, you know, I think a lot especially with the young people (Transcript 15 CW).

The belief in God that good is rewarded with goodness and blessings, and evil with punishment can be linked to such perceptions. A few African-Caribbean men and women and black African women held similar views especially those who had a strong belief in God. Black African men in the study did not seem to express this view although this did not mean that they did not believe in God.

4.3.9 Other Perspectives

4.3.9.1 HIV and AIDS as Positive Experience

The experience of HIV and AIDS is generally negative as HIV positive patients struggle to maintain a normal identity and to cope with enacted and felt stigma. In this study, although a majority of the study participants felt negative about their positive HIV status, and perceived HIV and AIDS as a negative experience, two participants however found being infected with HIV, a positive experience.

When I came here it was advised that my partner comes in as well. That was the problem so it's like me and my partner are in the same boat now. If it's anything, it's amazing; it's brought me and my partner closer (Transcript 17, CM).

A similar experience was expressed by a black African woman who declared having found true love with an HIV negative partner after disclosing her positive HIV status to him.

..Infact I am beginning to think that, you see, this diagnosis is a good thing in a way. It has been a good thing for me because I didn't think that I will meet someone like that. I didn't think you could meet someone and they know that you have HIV and they still want to be with you and an African, well a guy with African parents and he's my kind of guy (Transcript 11, AW).

No black African man and no African-Caribbean woman found being infected with HIV a positive experience. The emergence of positive experiences with HIV infection may be a

signal to greater understanding of the HIV life cycle by participants and possibly by the population in general.

4.4 Knowledge about HIV and AIDS by Ethnicity and Gender

4.4.1 Knowledge by Ethnicity

General knowledge about HIV and AIDS among black Africans and black African-Caribbean participants has been compared throughout the chapter but the following paragraph provides a summary of key similarities and differences among these two groups in terms of knowledge about HIV and AIDS. Comparison by gender is also presented. Both groups showed some variation in knowledge but generally all the participants manifested and expressed gaps in knowledge related to HIV and AIDS. For instance, all participants from both backgrounds were unaware that HIV was different from AIDS and most of them perceived HIV and AIDS as a death sentence. Additionally, all participants had received information about HIV and AIDS at the clinic. Although they felt that the information was insufficient, all of them were uneasy with leaflets as the main source of information justifying their unease to the high potential of unintended disclosure. African-Caribbean people generally were more open than black Africans about their HIV status. They appeared to be more aware of the availability of HIV facilities and were more likely to practice prevention unlike black Africans who appeared to be unaware of such facilities and were less likely to practise safer sex.

4.4.2 Knowledge about HIV and AIDS by Gender

There were also minor variations in knowledge by gender. Men more than women in the study were more open about the modes of transmission of HIV and AIDS and were more

likely to recognise the biologic basis of HIV and AIDS unlike women who recognised HIV and AIDS as punishment from God and strongly held onto lay beliefs or conspiracy theories about its origin. Both men and women showed gaps in knowledge and information about HIV and AIDS and this was reflected in their help-seeking patterns. Both men and women did not understand the difference between HIV and AIDS. Information and knowledge about HIV and AIDS are essential in motivating people to seek help. Such gaps in information and knowledge explain the different perceptions of HIV and AIDS held by participants which affected their help-seeking behaviour.

4.5 Summary

HIV and AIDS were understood by participants from many different perspectives although all these perspectives reflected insufficient understanding of the disease. Surprisingly, this lack of understanding was verbally expressed by the participants. The lack of understanding implied that people could not make informed decisions to prevent HIV or to test voluntarily. However, a greater understanding of HIV and AIDS appears to be emerging among some of the participants. Interestingly, there was no significant difference in HIV and AIDS knowledge among both groups and among men and women.

4.6 Conclusion

Although HIV and AIDS are common and widely known names, little is understood about what they really mean. Furthermore little is known about how they differ, implying that there is still great need for knowledge and information about HIV and AIDS. Insufficient understanding of HIV and AIDS has resulted in the disease being perceived in many different

ways both by patients and the general public. While black Africans participants may attribute their HIV status to behaviours, practices, attitudes and attributes (which have been termed ‘Africanness’) well known to them, it is interesting to note that some African-Caribbean participants held similar views about black Africans, culminating in their belief and naming of HIV and AIDS as a phenomenon of ‘Africanness’.

The following chapter (Chapter 5) therefore explores the taxonomy of the term ‘Africanness’ in the context of this study. It analyses the different attitudes and behaviours that have been described by black Africans and African-Caribbean participants in terms of ‘Africanness’ and shows how the ‘African thing’ and the ‘African way’ can be conceptualised as risk in the context of HIV and AIDS.

Chapter Five

‘Africanness’

5.1 Introduction

Knowledge and information about HIV and AIDS by study participants have been the focus of Chapter Four. Although the chapter highlighted the greater tendency of participants to perceive HIV the same as AIDS, it highlighted other different perceptions of HIV and AIDS by participants in general. Also, in chapter Four, eight of the participants thought that only black African people get HIV and AIDS. The current chapter broadens the scope to look at the broader context of participants of black African culture and behaviour and its relation to HIV and AIDS.

The current chapter (Chapter 5) examines ‘Africanness’. ‘Africanness’ is a term that embodies attitudes, attributes and behaviours of black Africans that are thought to place them at risk of contracting or transmitting HIV and AIDS as described by participants themselves. ‘Africanness’ was portrayed in many contexts in the current study and has therefore been used to embody everything referred to as ‘African’ by participants. For instance some participants described HIV and AIDS as ‘African thing’, ‘African way’, and ‘African illness’. All these highlighted the notion of ‘Africanness’. ‘Africanness’ was therefore one of the main themes that emerged from the data. While it may be assumed that the notion of ‘Africanness’ is common only among black African participants, interestingly, some African-Caribbean participants also referred to some of the black African attitudes and behaviours in terms of ‘Africanness’. This chapter therefore, analyses the different contexts of ‘Africanness’ as used

by participants. The chapter justifies the perceptions of HIV and AIDS as ‘African thing’ or ‘African illness’ in the context of ‘Africanness’. The different contexts of ‘Africanness’ as portrayed by participants in the study are analysed to show how these contexts may constitute ‘risk’ in relation to HIV and AIDS. The chapter ends by comparing the different perspectives of ‘Africanness’ among black Africans and African- Caribbean people and among men and women in the study.

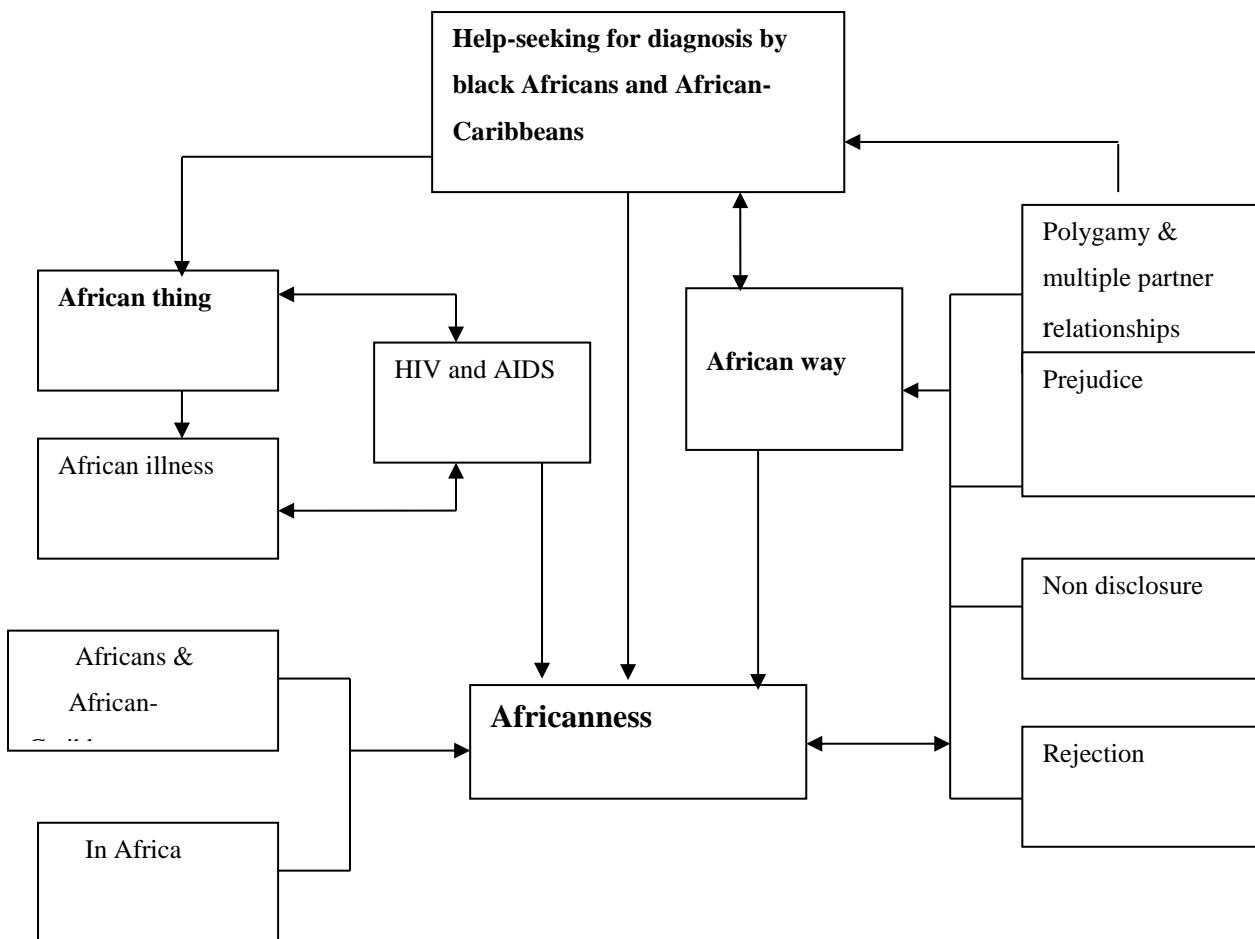


Figure 1: ‘Africanness’ and Help-Seeking

5.2 ‘Africanness’

‘Africanness’, as used by participants, embodied many risk factors related to black Africans in the context of the study such as multiple partner relationships, prejudice, non-disclosure and rejection. It is also seen as HIV and AIDS itself (Fig. 1). ‘Africanness’ brings to mind the notions of ethnicity and race described in the literature. ‘Africanness’ which referred to shared attributes among black Africans in the study was used by participants in this context to reflect a shared African culture that fostered a sense of African identity. Also attitudes and practices such as polygamy and multiple partner relationships, issues around disclosure (strategies to maintain a non-discreditable identity), rejection and prejudice described in terms of ‘Africanness’ were referred to as ‘African way’. The reactions of black Africans of the knowledge of one’s positive HIV status were described as ‘African way’.

When you go into the country and you meet with other people and `they know you are positive. Oh my god, you are cursed! You are in Africa, yes you are, you are cursed; that's an African way! (Transcript, 2 AW).

Concealing an HIV positive status by falsification and fabrication of test results was described by some of the participants in terms of ‘Africanness’. For example, the following participant in the study referred to bribery in order to obtain fake medical evidence of a negative HIV or AIDS status in the UK as an ‘African thing’.

Those things they do bribing people [to provide fake documentary evidence that they are HIV negative]. That is ‘African things’ not over here [UK] but they bring it over here, doing those things but you know that you are infected with HIV. We must

protect the innocent people; don't just go killing people and showing them fake papers like you're not infected with HIV positive, somebody will believe you and you are killing the innocent (Transcript 6 AM).

Issuing documents with false diagnosis appears to be a worldwide issue. It would appear that while this practice may be discrete in other countries it is popular practice in Africa. Shilts (1987) highlighted this practice in America among white and black Americans especially during the early years of the HIV and AIDS epidemic during which physicians falsified death certificates.

There is no documented description that embodies all these attributes of 'Africanness' such as the ones outlined in the above examples. Without any such documentation, the likelihood is that 'Africanness' can be described in many ways to suit the context in which it is being used. Being used to mean different things although all related to HIV and AIDS risk behaviour, implies that there may be many more practices, behaviours, attitudes and attributes which can be described in terms of 'Africanness'. These may be beyond the scope of this study and claims cannot therefore be laid here that 'Africanness' is 'exhausted' in these analyses. The different perspectives of 'Africanness' that are presented and discussed in this chapter are limited to those emerging from the data. 'Africanness' in the context of this study therefore may best be described as the attributes, behaviours, attitudes and practices that are common among black Africans of which they are aware and accept that these form part of their identity as Africans. It is also worth noting that 'Africanness' is a major theme in this study especially because not only did black Africans recognise it but more importantly, it was also recognised by African-Caribbean people.

5.2.1 HIV and AIDS as ‘African thing’ or ‘African illness’

HIV and AIDS have long been recognised as an African illness not only by Africans but by the entire world (Shilts 1987). Some black African and African-Caribbean participants in the current study referred to HIV and AIDS as ‘African thing’ and some as ‘African illness’. African women in particular in the study generally recognised HIV and AIDS as an ‘African thing’. Their perception of HIV and AIDS as ‘African thing’ appeared to have been influenced by the large number of Africans that attended the clinic for HIV and AIDS related care compared to other ethnic groups. A participant confirmed,

I think this disease is an ‘African thing’, I see lots of African people here! I don’t seem to see many people from other places, just African people. (Transcript 4, AW).

The ascription of the name ‘African illness’ tended to also be considered as a western invention by some black African participants. According to them, it was a population control mechanism on African countries imposed by the ‘white man’.

It is the White man who bring it [HIV and AIDS] to black people because they want plenty black people have it so they call it black people sick. I don’t trust them. They take it to Africa and they say Africa people have HIV. I tell you, they say they want to reduce black people population (Transcript 23 AM).

Five African-Caribbean participants had similar views with black Africans and perceived HIV and AIDS infections as an ‘African illness’.

It is prostitute them get the sick. African people too, them get the sick [HIV] too much. People them have the sick, they, them die young. Woman I go have sex with, them not prostitute and me use them thing er..boots all the time. That is why me tell you say, me think that boots burst man (Transcript 20, CM).

Four African-Caribbean men also perceived HIV and AIDS as an ‘African thing’ to the extent that they highlighted that, African-Caribbean men would only practise safer sex with black African women and not with non-African women. It was also reported that African-Caribbean women had a similar view of black African men when it came to a sexual relationship.

They think it is just from African people, it comes from, an African thing and I know different now. Eryeh they worry about it, but I have witnessed, not actually witnessed, I’ve seen, I’ve seen friends, but I have seen friends who have practised unprotected sex but at the same time they fear HIV and AIDS. Er I have seen mixed messages, ya, but here it is amazing, the ignorance and inexperience, yes. They think if I am gonna make love or have sex with an African lady, I am going to use a condom but I have heard women also say ‘if I have to have sex with an African man, I will use a condom’ but it seems as if they wouldn’t use a condom if it is someone else because they think it comes only from African people (Transcript, 17 CM)

Three African-Caribbean women also perceived HIV and AIDS as an ‘African illness’. This was the case because of the high number of black Africans they met at the clinic.

When I come here, the more people I seem to see are Africans. I don't see many Jamaicans here. I mean the person I think, I think that gave this to me, he's from Jamaica. It is clear that, that one person doesn't, I don't think they, like in the Caribbean because they don't have the teaching. It's only now that they are doing education (Transcript 25 CW).

They [the public] know it [HIV] is very bad illness and it's people who go after women or men that get it; them prostitutes or something like that. Some people think that it is punishment from god and when you get it you die. Some people say it is sickness for African people. I see many African people with it in Birmingham. We receive treatment together (Transcript 26 CW).

Surprisingly, African-Caribbean participants recognised HIV and AIDS as an 'African thing' or illness meanwhile they are not Africans and HIV and AIDS is worldwide. This may be related to their awareness of the high rates of HIV and AIDS related deaths in Africa and the large number of Africans that attend the clinic for HIV and AIDS treatment. As such, they perceived HIV and AIDS as 'African thing' based on such observation. For example, the following African-Caribbean participants referred to HIV and AIDS as 'African thing' because of the number of Africans that were infected which was reflected in the clinic attendance and information about HIV and AIDS in Africa.

I also think it is an African, an African thing; because you have many Africans suffering from it. You always have many of them in the clinic here and they also say many people die in Africa of HIV and AIDS. I think it is an African thing because almost everybody have it. I think some go to other hospitals too (Transcript 10, CM).

I used to go to some clinics in Birmingham and there were a lot of Africans and as I said, the Jamaicans don't like to come to hospital. I don't see Jamaicans but I see many Africans. Here too I don't see Jamaicans but I see Africans, plenty of them especially women. (Transcript 26 CW)

On the contrary, a few participants felt that the rates of HIV and AIDS infections portrayed in Africa by western countries were inappropriate and did not amount to HIV and AIDS being an 'African illness'. They noted that any illness or even famine in Africa which was not HIV or AIDS was presented by the West as HIV and AIDS and this to them is an attempt to maintain subordination of the black race. Some participants in the study still held conspiracy theories and lay beliefs about the cause of HIV and AIDS. For example, the following participant believed that HIV and AIDS was artificially manufactured in the western countries and exported to Africa and the Caribbean in foods and medications.

Be wise, it's better to know than not to know, and you carry this thing [HIV and AIDS] and you don't know and when you get it, when you start getting ill you don't know why you're ill, so things like that, so through the media, its going to be very negative, because it's very negative now because, three quarters of the, if you look at some of the programmes and you see, and I'm saying, hold on a minute!, I've seen pictures, black people dying, you know I'm not sure what is going on. I am sure I have seen this picture of Ethiopians; they had the famine there and they put all this to make out that we, and if you look at history, yes it's all around, but the proportion of what [HIV and AIDS] they're saying in Africa, ninety odd per cent!; that's rubbish, that's a lie, the only way that can happen is that you're, you're creating that drug, and

you're literally putting it in food. If we stop taking all these milk powders and go back to the natural way of breast feeding, go back to our natural herbal remedy, I think we can't go wrong, we cannot go wrong (Transcript 15 CW).

Lay beliefs and conspiracy theories may be misleading as the focus of HIV and AIDS causation is likely to be diverted by such beliefs. These types of perceptions are what people consider as the real causes of HIV and AIDS, explaining the divergent views in help-seeking. Switching back to nature and discarding the current trend of treating illness and diseases explains the covert intentions and real habits of unsafe sexual habits and delays in seeking help. This participant on the other hand may also be making a point here based on the history of public health services with African Americans (Bogart and Thornburn 2005, Bird and Bogart 2005) such as in the Tuskegee syphilis study of 399 sharecroppers observed without treatment till their death, which lasted for forty years (Jones 1993). Such occurrences have a tendency to instil in people a tendency to distrust public health activities aimed at black African and African-Caribbean people.

5.2.2 Polygamy and Multiple Partner Relationship as 'African way'

Some of the participants in the study recognised polygamy and multiple partner relationships as an 'African way'. This perception was common among black African participants and mostly among women.

Well he [my husband] moved, he moved, it wasn't really, I'm, I'm I was married in church with him (laughs) but he kept on moving with other women like, you know the African way, but men, African men, you can't stop them. I am sure that is how he got infected [...] Oh yes! Hmm we knew. He had HIV and we knew that, and some of the

co-wives had died before him. I suspect, I suspect they all died of HIV. But you know, my husband was in denial right to the end. He had a position and he had money too. He moved with so many women (Transcript 2, AW).

Multiple partner relationships or polygamy did not feature in interviews with black African men. Because these types of relationships are recognised as a normal black African way of life, the men probably did not find it necessary to talk about them. However a few black African women in the study acknowledged polygamy and multiple partner relationship as an ‘African way’ which constituted risk for HIV and AIDS. Black African women were aware that such types of relationships were to blame for HIV and AIDS infections in black Africans. Some black African women in the study noted their husbands’ multiple partner relationships not only as the source of their HIV infection but also as a source of unhappiness in their relationship. For example the following participant had marital problems when her husband attempted to engage in another marital relationship and she recognised it as an ‘African way’;

I found a man here and we went back to Uganda and got married in the church that I used to go to before I came here. I came back here before him and he stayed back and started having an affair with another woman telling her he will marry her, typical African! I learnt about this. When he came back he will be phoning the woman, sending her text messages and emails. This caused so many problems in our marriage so.... (Transcript 5, AW).

Although it may be generally assumed that black African women are happy with polygamous marriages or multiple partner relationships since it is an African way of life, this may not always be the case. Polygamy or multiple partner relationships did not only constitute a risk

factor for HIV and AIDS infection but also a source of unhappiness for the black African women as highlighted in the above example.

Economic power was blamed by some of the black African women on their husbands' desire for polygamy or multiple partner relationships that exposed them to HIV and AIDS infections. This is recognised as the powerlessness of women and evidence of male domination through economic power (Jacoby 1995).

And I did not even enjoy being with that man [her husband] you know. You get married when you are 23yrs and get children and the man dominates you, all because he has got some money and he is not even from your tribe (*ah, shakes her head*), and he goes after every woman, oh! all those regrets were there anyway ... (pause). He was from Zimbabwe! I do not think he really cared anyway (Transcript 2, AW).

Black African men in the study did not talk about polygamy or multiple partner relationships, but they were aware that such relationships constituted risk for HIV and AIDS but at the same time it is an African way of life. It is believed that polygamy in the African society resulted from the desire of men to demonstrate economic power and such was measured in terms of family size. For instance, the greater the number of children a man had, the wealthier he was perceived to be. This desire therefore supported the need to have more than one wife and hence engagement in multiple partner relationships. Although the common perception of polygamy by non-Africans is that the black African woman is suppressed as a result of such practices (Adams and Mburugu 1994), the perception of polygamy by black African women themselves varies within and across societies (Kilbride 1994). Madhaven (2002) suggests that women's perspective of polygamy as well as their experiences can best be understood within

a personal and socio-cultural context. Some participants in the current study highlighted their lack of choice in matters of polygamy or their partners' engagements with multiple partners as an 'African way'.

You know in Africa women can't really say much in those lines [decisions about polygamy] but being from Uganda was a limitation of how much I could do (Transcript 2, AW).

Some participants in the current study associated their source of infection to their husbands from their multiple partner relationships, for example, the following participant compared her marriage with a polygamous marriage and blamed her infection on her husband's multiple partner relationships and she recognised it in terms of 'Africanness'.

I was really touched [that I was infected with HIV] because I was so faithful to him (laughs) and I got few of my co-wives. The wives have passed. It was like a polygamous marriage [...] hmm... (ok, ok) well he moved, he moved, it wasn't really [a polygamous relationship], I'm, I'm I was married in church with him (laughs) but he kept on moving with other women like, you know the African men [*our voices overlapping*] but men, African men, you can't stop them. I am sure that is how he got infected (Transcript 2, AW).

Being aware of a husband's involvement in multiple relationships does not appear to affect the black African woman as such a relationship is understood as a cultural practice and this is compounded by the powerlessness of women. The legalisation and recognition of polygamous relationships make it worse. Polygamy is grounded in the culture of Africans.

Despite the Christian doctrine that prescribes monogamy and chastity, black African men do not pull away from practising polygamy. Subscribing to monogamy just serves as a condition for men to go through the Christian marriage rituals. Christian marriages do not stop them from breaking away from monogamy to polygamy or having multiple partners. All these behaviours are acquired from the African culture of polygamy, enshrined in the legislations of many countries. These legislations are hybrids of legislation adapted from western culture, yet grounded on African culture.

5.2.3 ‘Silences’ and ‘Broken Narratives’ as ‘Africanness’

Various strategies for recovering from a ‘discreditable’ status (HIV positive status) or for managing information related to disclosure of a ‘discredited’ status were used by different participants in the study both from African and African-Caribbean backgrounds and these embodied either ‘silences’ or ‘broken narratives’ or dishonesty about their true diagnosis. The terms ‘silences’/‘broken narratives’ (Drakos 2008) are used to describe the behaviours manifested by participants after knowledge of their HIV status as ways of maintaining a normal identity. The issues around disclosure of an HIV positive status may be universal and not exclusively an issue of ‘Africanness’ as perceived by black African participants in the study. Shilts (1987) noted the failure to acknowledge the AIDS epidemic by victims at the start of the epidemic and highlighted attempts by doctors to conceal the truth through falsification of death certificates.

5.2.4 Strategies for recovering from a Discredited Status

In the current study, different participants used different strategies to retrieve and maintain their previous status of ‘normal’ and some of these strategies were ‘silences’ or ‘broken narratives’; for instance the following black African participant did not disclose to his family

his HIV positive status but used a more acceptable status to describe his health condition in an attempt to be ‘normal’.

No, that time I was, I didn’t talk; that time I was in hospital and my sister – in – law, she used to come and visit me every week and her husband try to ask me what was the problem but I tell them it is a kidney problem (Transcript 8, AM).

A positive HIV status is a ‘discredited’ (Goffman 1963) status and earns the affected individual a ‘spoilt identity’. In order for the individual to conceal this identity and appear normal and acceptable to others, one of several strategies may be used. Some of these strategies include the management of information about their identity and the management of their recovery from the ‘discredited’ status to retrieve the previous status of ‘normal’ i.e. none ‘discredited’ person. Strategies to maintain a ‘normal status’ appeared to be used both in and out of Africa and were used both at individual and institutional levels.

I told her [my step daughter] that I had a kidney problem, and that social worker was so good that she went into lies with me. She [social worker] came home because I was so sick (laughs) and told my step daughter that, oh, well, we have got a kidney problem here! These are the symptoms; we are watching it and she will be alright within six months (Transcript 2, AW).

Such a strategy is consistent with broken narrative although it contained an element of dishonesty. This strategy to portray an acceptable identity by not being honest about their diagnosis was also used by one of the participants in her local church when she requested for prayers for healing.

No, well I did tell them [my church] I've got hepatitis, which I do have. It's not like I don't have it but I haven't given them a true picture of all I've got (Transcript 3, AW).

Some black Africans in the study suggested that the choice to keep silent about their diagnosis was related to black Africans' reactions to knowledge of a positive HIV status. Whereas this type of attitude seems to be common in non-African countries as well, black Africans in the study believed that it was a black African attitude. Their rejection of victims is potentially supported by cultural factors.

The minute you tell one person [that you are HIV positive] the next minute the community will all be looking at you. If I tell especially an African here, the next minute all the Africans will know [that I have HIV] like in Africa, and you will have no friend. And the family will not want to come near you, you know what I mean, they will keep their distance. So for me to be happy, I'll, I..er.. have to keep it to myself (Transcript 24, AM).

Some participants described rejection by family and friends in terms of 'Africanness', after knowledge of their positive HIV status as their justification for keeping silences.

My reasons for wanting to keep it to myself; my reasons, er one is that I know that Africans; er...er. I'm (giggles); I am being a bit racist here but it is not that I am racist but I'm talking from my own experience. Er... I know that if I reveal the secret to my friends who are illiterates, who don't know much about the sickness these days, the stigma, you know the stigma; they will think ooh! This is my friend, she's got HIV! I

don't want to come to her house again. I will not eat from her and that will make me feel more bad; you understand, so there is no need to reveal it; to keep it and then do the right thing that's it! that's what I want to do because if I tell my friend, they would say, what about if I go to her house and she cooks maybe something happens and she give me the sickness, so it is between me and my husband, that's it! (Transcript 19, AW).

There are many reasons for maintaining silences about an HIV status as has been described in the preceding paragraph. Apart from stigma, other reasons suggested by participants included the fear of getting infected by eating food prepared by an HIV positive patient. This suggests the need for education and information about the transmission of HIV and AIDS.

5.2.5 Strategies for managing information

Participants in the study had different ways of managing information to avoid breaking ‘silences’ (disclosing) about their ‘spoilt identity’. This may be very challenging as the individual may not feel free taking his/her medication or learning more about HIV and AIDS to avoid any source of suspicion from friends and family that they are infected. Attempts to appear normal suggest that while the virus continued to destroy their immune system and exposing them to advanced stages of the illness, potentially, the patient continued to spread the disease to others.

I will not share [HIV status] with my family, no!. I am not lying to them. I'm not having to tell them. I'm not lying to anyone (tearful!) but the fact is that I am not talking about certain subjects, full stop. If it stays within me, if I die it will go with me. That's it! (Transcript 21, CM).

Some participants were very selective about who to tell and what to tell (broken narratives) and were still worried about meeting people they knew or accidentally disclosing their condition. For example, the following participant had to modify his behaviour to avoid unintentional disclosure of his HIV status.

I couldn't be as comfortable in the way that I socialise with other people. I am aware that any encounter, sexually, any sexual encounter could lead to disclosure for the other individual so that was something I was very afraid of so I had to alter my behaviour as such so I think that is a situation where people have to be aware of their behaviour and change or be aware of their own mortality other than that they are not confident that you know, live happily over my normal life span (Transcript 22 CM).

The struggle to keep 'silences' about their HIV positive status as in the above case suggests that people failed to learn more about their ailment and to encourage others to test thereby making control of the epidemic challenging. Disclosure appeared to be selective and tended to depend on the nature of the relationship or on the amount of trust in that individual to whom disclosure was made.

Yes my wife and me friend. We work at garage. Him, he got his own garage. Me have my own garage. We go after women together but we use them boots all the time and come do blood test every year. Me wife have to come test ..er.. she can start treatment. After blood test they come say she not have the illness. Me not on treatment yet you know, me come for blood test every month but docta say me no need medication just yet (Transcript 20 CM).

Disclosure also appeared to be based on perceived consequences on family members or loved ones. The following participant disclosed his HIV positive diagnosis only to his siblings but not his mother.

My sister said to me, oh! you should tell mum [about your diagnosis] but I can't because mum is not very well, she is diabetic, she's very ill, she's under the care of social services as well every Friday. I don't want my mum to be dealing with this stress at 72 because she brought us up and I don't want to add that stress to her, She did ask me once because she is very observant but I just told her it's just a very bad blood condition and I have to take that tablets, I couldn't tell her it's HIV cos I know she couldn't deal with it (Transcript 14 CM).

The extent of disclosure also appeared to be based on the physical and mental ability of the participant. The following participant's diagnosis was disclosed to his family because he was very ill but he would normally not disclose it to anybody if he had the choice.

Well, my mother was there and other family members were there when they gave my diagnosis because I said I collapsed, so there wasn't really much choice (Transcript 9 CM).

All black African participants were either silent about their HIV positive status or they did not disclose their real diagnosis. Such practice appeared to mislead people about the true extent of HIV infections. For example, the following participant together with a health institution was dishonest about her husband's diagnosis at his death. She expressed that such practice is common in Africa and black Africans know it as an 'African way'.

Because they were not here when he [their father] fell ill, so they just came to see him on his death bed and then, he had thrombosis in the beginning and we just created a story and when they asked this, what their father died of and, in Africa, everything is possible. They ask for a death certificate and it was issued with another type of....
(Illness)....hmm. We knew but we let it to be that way (Transcript 2, AW).

HIV and AIDS patients may only be able to conceal their positive status for a short period. This may depend on the length of time before the appearance of symptoms but the desire is to conceal the symptoms from the outside world and appear normal as described in the literature. Unfortunately, there comes a point when they are unable to conceal signs and symptoms of the disease at which stage they become discredited. This may not have parallels with other terminal illnesses such as cancer which seems to illicit sympathy from the public. This may be so because infections with HIV and AIDS are likely to be blamed on the individual's risky sexual behaviour and when people do not feel comfortable to seek a diagnosis in order to start treatment; numerous signs and symptoms may start to appear.

Alonzo and Reynolds (1995) suggested that although HIV and AIDS positive patients conceal their status, it is not an adequate strategy for avoiding the pain of illness related stigma. They suggested that although fear of discovery is high, attempts to conceal their symptoms may result in limited social interactions. Even though one of the consequences of such behaviour is the inability to form intimate relationships, friends and family may start to question the change in behaviour which may place the patient at further unease. Keeping silent is a way of maintaining the secrecy described by Simmel (1906) and Goffman (1959).

Diseases and illness in Africa, especially diseases perceived to have originated from another culture are not given specific names. They are merely described and identified through disease symptoms (Awah et al 2009). There is no African language that would call such a disease with a name as given by biomedicine. An ethno-biomedical perspective is taken to name it (Awah et al 2009). Africans have learned that culture, and are more comfortable in recognizing and naming a disease from its symptomatic perspective. Therefore, the opportunistic infections that follow an HIV person is a comfortable way for a black African to describe his ill health in a way that is known and accepted by the culture to which he belongs. Illnesses are described and not diseases. Describing the illness means acknowledging the existence of that unnamed HIV positive status. Although black Africans in the study believed that ‘silences’ as a way of managing information to avoid disclosing their status was uniquely an ‘African thing’, the above section provides evidence that this practice is widespread in African-Caribbean communities.

5.2.6 Rejection as ‘Africanness’

Black Africans in the study also described rejection as an African attitude after knowledge of one’s positive diagnosis and noted that this attitude was still common among black Africans in the UK. The study also showed that rejection was far from being only an ‘African thing’ or an individual thing. Rejection also seemed to be an institutional practice in the UK. For example one of the participants in the study was dismissed from her job in a UK institution following disclosure of her HIV status to her employer. This may be seen as an example of institutionalised rejection and the failure to apply the Equal Opportunity Law in Employment. The Equal Opportunity Law requires that employees are not discriminated against on grounds of their HIV positive status. This also shows that HIV is far from being accepted as a chronic illness and therefore the potential for stigma is still high.

The same day (laughs) hmm, basically what happened was, I told her [the occupational health nurse, that I have HIV]. She called the director of nursing and ...er she said she was suspending me indefinitely for the safety of my patients and myself. From there I had to be represented at a hearing. Before they suspended me I had a disciplinary hearing. After the disciplinary hearing they dismissed me (Transcript 25 CW).

While black Africans believe that rejection of HIV positive patients by family, friends and institutions is ‘Africanness’, it appears to be widespread in the UK by White British people and some institutions. It has been reported in African-Caribbean communities among families and friends.

I know what my friends and my family think about HIV. I have heard them just in general chit - chat that erm... that it [HIV and AIDS] is something really bad to them. Even before I was diagnosed, I used to be like them. I am sorry, yeh I used to be ignorant like them yeh, but the reason why I haven't shared it with them is that I feel and I definitely know that I will be shunned. They will keep their distance from me. I hate..ier when I think about it I hate to think that if I do, what will really happen but I know they will keep their distance (Transcript 17 CM).

Rejection because of a positive HIV and AIDS diagnosis in Africa involves everyone regardless of the relationship with those rejecting the patient. For example the following black African woman noted that even her own children would reject her if she disclosed to them her HIV and AIDS status:

But in Africa they will throw me out, they will hate me they will ostracise, me, they will segregate me, all that sort of thing and it...is still there, it will never stop. So if I told my children, you will see me with nobody (Transcript 2, AW).

Although black Africans perceived rejection as an African way probably because it was much too common in Africans infected with HIV and AIDS both in Africa and the UK, African-Caribbean people did not view rejection as uniquely an ‘African thing’ and as such did not refer to it as such. There were indications among African-Caribbean participants that rejection was also common in the African-Caribbean communities.

5.2.7 Prejudice (Being Judgemental) as ‘Africanness’

Almost all the black African participants mentioned ‘being judgemental’ in relation to HIV and AIDS as common in Africans. Although it might be a common phenomenon in other countries, African-Caribbean participants did not mention it but the following black African participant found it very unusual for an African to be non - judgemental.

I didn’t think I would find an African person, as such because they’re very judgemental. Ok first and foremost they might think oh, she’s been a prostitute and all that but I work very hard [...] I have never been a prostitute. I’m not a prostitute. Even prostitutes because no one knows why they’re doing what they are doing. I can’t judge anybody but only if Africans will remove the element of judgment and realize that we’re all going to die anyway somehow (Transcript 11, AW).

Some participants noted that prejudice against HIV and AIDS patients in Africa did not only affect the infected individual but involved the whole family e.g. the following participant highlighted the negative effects of her HIV status if she was in Africa.

I've still got younger sisters who haven't yet married. People will say, ooh! Ok, there is somebody who has HIV in that family so they wouldn't go to that family. So my sisters will suffer because of my own sins or because of my own affliction. People might not go there. They might think that everybody in the house has got it
(Transcript 3 AW).

As noted in chapter 2, illness especially in the African context is a family and not an individual issue. Similarly, the consequences of an illness are also not an individual issue. This practice can potentially increase the determination of victims to conceal their HIV diagnosis.

5.3 Impact of ‘Africanness’ on Help-seeking for diagnosis

As discussed in the preceding section, ‘Africanness’ means different things to different people and in a way ‘Africanness’ constitutes risk in the context of HIV and AIDS. ‘Africanness’ seemed to impact negatively on help-seeking for diagnosis to some extent. For instance, rejection of HIV positive patients by their families and by society in general and the inability of friends or the public to keep information about one’s HIV status confidential, probably impacts negatively on help-seeking. This implies that people may not have the tendency or the willingness to know their HIV status for fear of rejection. This may also

imply that people are diagnosed at an advanced stage of illness when they may no longer be able to conceal or contain their symptoms.

Also being judgemental towards people who are HIV positive may constitute a potential barrier for testing. The thought of being referred to as a prostitute as expressed by some of the participants did not seem to be pleasant to them. The fear of being addressed or perceived as such may impact negatively on the desire to seek help for diagnosis of HIV and AIDS and therefore may deter people from testing.

‘Silences’ or ‘broken narratives,’ may also impact negatively on help-seeking for diagnosing HIV and AIDS. The struggle to manage a ‘spoilt identity’ through managing information about their health status as well as strategies used to maintain normality by the infected individual, suggest that people with symptoms fail to seek help for fear of the consequences.

One of the participants was not happy that his HIV positive status had been revealed to his GP without his consent and felt that his chances of eligibility for processes like mortgage applications, insurance and job application had been jeopardised as the GP will not be able to conceal this information when required. Such feelings suggest that the determination to keep silences about an HIV diagnosis go beyond the fear of stigma. The desire for health insurance and the need to have a mortgage, for example, suggests that people fail to disclose their HIV status or fail to seek help even with symptoms.

Silence, denial and concealing of an HIV positive status and stigma may affect the way that people seek help for it. It is more accentuated among black Africans and African-Caribbean people living in the UK. It may be felt more within the black African communities, more so

because of the way the disease is named and the way people with the disease are treated within families and the larger society. However, a more acceptable approach to victims and members of their community may be naming the disease through its symptoms or asymptomatic infections. That may make seeking health care acceptable.

5.4 Comparing African and African-Caribbean Perspectives of ‘Africanness’

There were similarities and difference between black Africans and African-Caribbean people in their perceptions of ‘Africanness’. As highlighted above, ‘Africanness’ in this study is seen in the context of ‘African thing’/ ‘African way’, polygamy and multiple partner relationships, silences, rejection and being judgemental. The study found that not only black Africans believed that HIV was an ‘African thing’ but almost all the African-Caribbean participants associated HIV and AIDS with black Africans. They either believed that it was an ‘African illness’ or an ‘African thing’ to the extent that they believed it was normal to have an unsafe sexual encounter with anyone else other than with black Africans. This however may not be surprising as there is much literature suggesting that not only did HIV originate from Africa but that Africa is the most affected continent.

5.4.1 Perspectives on Multiple Partner relationships as an ‘African way’ by Ethnicity and Gender

While black African participants especially the women generally referred to the practice of polygamy or involvement with multiple sexual partners as an ‘African way’, African-Caribbean participants although they acknowledged their involvement with such relationships did not perceive HIV as uniquely an ‘African way’ or a ‘Caribbean way’. Polygamy is not

legally recognised or allowed in African-Caribbean countries although multiple partner relationships effectively exist. The current study showed that multiple partner relationships effectively existed among African-Caribbean people but were not recognised as a ‘Caribbean way’ by African-Caribbean people. Moreover, such relationships are outlawed by African-Caribbean authorities. From participants’ stories it was clear that multiple partner relationships were not only practised by men; women were very much involved in multiple partner relationships especially among African-Caribbean women. However, it is possible that black African women are also involved in such relations but this was not made explicit by them. This practice may also be common among other cultures but may be done discreetly. The following female Caribbean participants were unable to pinpoint their sources of infection because of their involvement with multiple partners.

I did not understand who gave this [HIV] to me, but I remember I had seen [had a sexual encounter] a man. I am not sure if he give me this HIV. I see a man but I did not plan it. It just happen...I did not see him for long time. Maybe like 3 or 4 times. I mean we had sex like 3 or 4 times. I did not plan it. It just happened. I suspect that it is him who give me HIV (Transcript 26 CW).

Well two of my partners, I know they are negative because it was not because of my diagnosis, we were just conversing and it came up that we would go to the doctor for test and what they’d done is that they were tested and they were negative. There was two of them, one person, the one I suspect gave me the sickness, I never found him and I don’t even know his whereabouts (Transcript 25, CW).

The risks involved in multiple partner relationships are made explicit in the above quotes. The acknowledgement of having multiple sexual partner relationships by some of the African-Caribbean men in the study, as well as the expression of doubts on their sources of infection by African-Caribbean women are not only evidence of such relationship among African-Caribbean communities but highlight the risks involved. The inability to pinpoint the source of infections implies that there is potential for a growing reservoir of infection in the community.

The study also highlighted the openness of African-Caribbean women in talking about their multiple partner relationships although some of them were in a marital relationship. No black African man or woman in the study openly talked about having had more than one partner before they were diagnosed. Engaging in such multiple partner relationships among some of the African-Caribbean participants appeared to be related to their low perception of HIV risk in their choice of partner group. For example, the following female African-Caribbean participant choose to have multiple relationships with people who were married with children as she perceived them as a low risk group for HIV infections.

No, not at all! In fact I didn't even think about it [any risks of HIV and AIDS]. I had partners but the partners that I have had, I never thought in my wildest dreams they could be positive. Because they had children, I never thought they could [have HIV]. I never thought really but now I don't know how I've got it. I don't know who from. But I just thought that I should test to know my status (Transcript 25, CW).

Paradoxically, it was the African-Caribbean participants that openly talked about such relationships while the black African participants (where such relationships are recognised

and accepted) in the study were less open about them in the context of their sexual practices e.g. the following African-Caribbean man was open about his multiple partner relationships.

But for the past 2 years, I too busy and I no come here to come get me self test. Me not worry to come because me always use ‘boots’. Me use to go after them women but me use them boots man! So it surprise me how me come get this thing [HIV]! (Transcript 20, CM).

Although black African women talked about such practices by their spouses, it appeared that knowledge of a male partner’s multiple partner relationships by a black African wife did not always seem to have negative repercussions on the marital relationship. This could be explained by the desperate need for a boy child in a girl dominated relationship or the need for a child in a childless relationship common in Africa. These needs seem to preoccupy the black African women to such an extent that even those women in a marital relationship that did not face such problems were able to contain their partners multiple partner relationships. It is not clear if this practice is similar among African-Caribbean women.

Nurse, sad! sad! sad! man. My wife know me say me do everything [have sex with other women] but me very careful with women. Me take cannabis and them things with me friends, and she know; me got condom always in me car everywhere. Right now me still have condom in me car. Me wife know me very careful but I think that boots burst man. But I don’t notice that ‘boots’ burst. Me shock, me wife shock too much (Transcript, 20 CM).

The above quotes suggest the high awareness among many of the study participants of the risks posed by multiple partner relationships in relation to contracting HIV and AIDS infections. Though polygamy is ‘the African way’ grounded in the African cultures and legislation, engaging with multiple sexual partners may not be exclusively African. African-Caribbean cultures, though not having polygamy enshrined in their legislation, allow them to engage in multiple partner sexual relations. African-Caribbean participants openly narrated their stories around multiple partnerships being responsible for their HIV infection. Conversely, this was not the case with black Africans where men were completely silent about multiple partnerships being the risk factor. However black African women attributed the men’s multiple partnerships to the cause their infections.

5.4.2 Silences (Broken Narratives)

All participants from both backgrounds kept silent about their diagnosis. Some did so for fear of rejection, some for fear of stigma and others for fear of being unable to get a job, secure insurance or a mortgage. Although both groups kept silent, the African-Caribbean group were more likely to tell their family about their diagnosis than the black African group who either falsified their diagnosis or were silent (Chapter 4). This practice was common among men as well as women. As discussed elsewhere in this chapter, while black Africans kept silent about their diagnosis they were more comfortable describing their symptoms.

5.5 Summary

HIV and AIDS is an illness that has affected black Africans and African-Caribbean people although to varying extents with black Africans more affected than African- Caribbean people. Black Africans tend to attribute these high rates of infection to some of their

behaviours and attitudes which have collectively been termed ‘Africanness’ although such behaviours and attitudes appear to be common in every society. This is common practice among black Africans and African-Caribbean populations. These behaviours have the potential to place them at risk of acquiring or transmitting HIV infections.

Many practices that have been described as ‘Africanness’ go unnoticed in other cultures but have been named ‘Africanness’ because of their close link to HIV and AIDS infections in the African society. The processes involved with contracting and dealing with the aftermath of HIV and AIDS also have been described in terms of ‘Africanness’. Polygamy and multiple partner relationships have been recognised as an ‘African way’ especially as it is legalised and practised as an African way of life. Although it is practised in the Caribbean, it is not recognised as an African-Caribbean way of life as it is not only outlawed but also not culturally accepted. As already stated in the chapter, it constitutes a high HIV risk.

Rejection, deception and prejudice are universal phenomena that are not exclusive to Africa although they are frequently used in relation to HIV and AIDS and are presumed to mean stigmatization and generate discrimination. However, these practices are very noticeable in Africa. Africans themselves have described these behaviours in terms of ‘Africanness’ and these have been seen to constitute risk in the context of HIV and AIDS infections.

The term ‘Africanness’ as described in this chapter, carries the notion of risk in the context of HIV and AIDS. Different participants in the study followed various pathways to seek diagnosis for HIV and AIDS. Their choices of the various pathways to some extent were as a consequence of perceived barriers to access.

5.6 Conclusion

A description of ‘Africanness’ remains ambiguous while the ‘African way’ seems to be clearly understood by participants as the risk factors for contracting HIV and AIDS or HIV status itself. The notion of ‘Africanness’ as used in the chapter, embodies everything that was referred to by participants in the study as African and appeared to influence the decisions to seek help although the type of help sought depended on the individual (Chapter 6). As illustrated in Figure 1, help-seeking may result in the diagnosis of HIV and AIDS, which participants felt comfortable referring to as ‘the African thing’. The next chapter (Chapter 6) examines pathways to help-seeking and analyses the barriers to access to health care in general as well as factors associated specifically with access to sexual health services by these groups of people.

Chapter Six

Pathways to Help-Seeking for Diagnosing HIV and AIDS

6.1 Introduction

The notion of ‘Africanness’ which described the attitudes, attributes and behaviour of black Africans and how they constituted risk in the context of HIV and AIDS has been analysed in the previous chapter (Chapter 5). The chapter also presented the different perspectives of ‘Africanness’ and highlighted the potential impact of ‘Africanness’ on help-seeking for diagnosing HIV and AIDS.

Participants in the study followed various pathways to seek diagnosis for HIV and AIDS. The current chapter (Chapter 6) analyses these pathways. The five main pathways identified included: 1) diagnosis through health promotion and secondary prevention (e.g. voluntary testing); 2) diagnosis in response to protracted symptoms that were unresponsive to self-medication; 3) diagnosis during hospitalisation for severe HIV and AIDS related illness; 4) diagnosis in response to health policy (i.e. screening in pregnancy) and 5) diagnosis as a response to the results of a partner’s HIV positive status. These pathways are presented on figure 2 below.

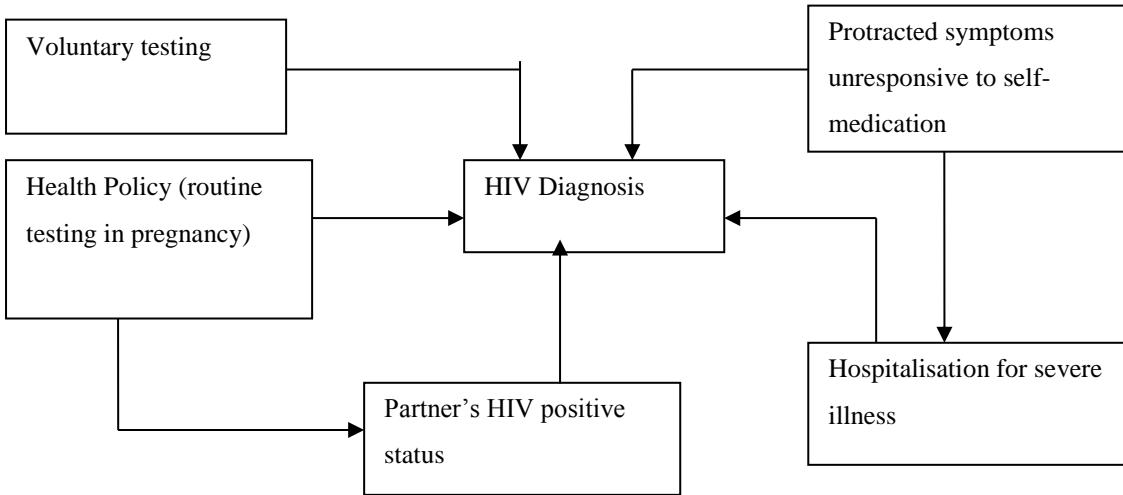


Figure 2– Pathways to Diagnosis

Analysis of these pathways provides some understanding of help-seeking behaviours of black African and African-Caribbean people to diagnose HIV and AIDS. An understanding of the rationale for the choices of different pathways chosen by people in general and the different decisions made to seek help for diagnosis have been discussed under the concept of help-seeking in Chapter 2. Some of the barriers to help-seeking to diagnose HIV and AIDS are analysed in this chapter.

The current study focuses on help-seeking with a problem and therefore will not analyse and discuss help-seeking that is targeted only for health promotion purposes (without any underlying illness). Various models of help-seeking (e.g. Rosenstock's 1968, Zola's 1973, Snow's 1974, Mechanic's 1978, Kleinman's 1980 and Leininger's 1991) have been presented in Chapter 2 and these models all provide frameworks for understanding some of the pathways that people chose in an attempt to seek diagnosis when they are ill.

6.2 Triggers to Help-Seeking

6.2.1 Response to symptoms and treatment options

One of the ways by which illness manifests is by symptoms. The responses to symptoms by participants in this study were diverse. While some of them responded spontaneously by seeking medical attention, others went through the process of lay consultation within the family and with friends before deciding on a further course of action.

I've got an older brother here who is a lab scientist as well. You know, when I was coming for the test, because we're very close, we tend to discuss a lot of things, you know, any medical problem, we will iron it out. He knew I had that genital boil and he encouraged me to come to the doctor (Transcript 3 AW).

Although symptoms might be present as indication of an illness, people with symptoms may not immediately seek help. This may be the case because help-seeking behaviour may also be dictated by social norms which demand that a health problem be both physically and sufficiently severe to justify the need to seek help (Richardson and Rabiee (2001). While it is possible that some of the participants ignored symptoms as part of adherence to social norms, others tried other therapies even before establishing the significance of those symptoms in terms of diagnosis.

I was having fever and cough. The cough stop and go and come back; my chest just full of stuff. Sometimes I have diarrhoea too. It will come on and go and come again. This one go on for a long time, like for 5 or 6 months. I will go and buy cough medicine from the chemist and the cough will go away today and come back and I

sometimes I just have pain in my body and I have fever as well. I was losing my weight too. I am trying to eat but I am only losing some weight and I don't feel well most of the time (Transcript 10 CM).

Well I went to er, at first I was still dealing with it [the symptoms], trying to address the symptoms whatever and after which I went to the private er.. Clinic (right) and asked for the test [HIV] since I still had the symptoms, I felt I had to address them (Transcript 24, AM).

Zola (1973) highlighted the various reasons people reacted to symptoms of illness and one of them is the significance of symptoms to them. Moreover (as stated in Chapter Five), illness especially in Africa, that is deemed to have originated from elsewhere is described in terms of symptoms and not the name of the disease. This is understood and is more acceptable to them than naming the disease. In this study however, symptoms were ignored by some participants and some had hope of a cure or relief of symptoms with self-medication based on the nature of their symptoms and failed to seek help even at a point when symptoms did not respond to self-medication.

.... I start to worry about sleep and pain. I was feeling pains and started to take more and more pain killers and I moved on to nurofen, a more stronger one and the problem is not getting better; all my body is paining and I thought this is getting more serious. I had pain on my leg and on my back and when I rubbed it with some medication, there was pus there. One day when I went to work I almost collapsed in the toilet so I took 4 days off because I want to see if I can try to fight the problem myself.... (Transcript 21, CM).

Other participants ignored symptoms for a long time with the hope that they would resolve especially as they were not such that restricted their daily activities.

The boils were, at first, at first, in the first year, they came once, hardened once so I thought it was only the friction there or something and I remember the 2nd year, the site, well it came back two times for that year, 2, 3 times and then that is why I started getting really concerned because I said, 'what is this, what is this thing? And then the 3rd year, it started to come once every three months so by then I said to myself 'something is wrong, let me go and get checked out at the GUM clinic' just to make sure that nothing is seriously, is happening to my body (Transcript 17 CM).

Symptoms were understood by some participants as illness in itself and not as an indication of illness. One of the participants had symptoms that appeared intermittently but understood this as an illness and not a symptom. Moreover, the ability of some of the participants to make a self-diagnosis suggests that the seriousness of the symptom was not perceived at the start and consequently the need for a medical consultation was not a priority at this stage.

More female participants tended to respond to persistent and unexplained symptoms than did the men in the study. This could primarily have been driven by the larger number of black African women consulting for symptoms, compared with African-Caribbean women.

..... I was getting very tired and weak ... During that period I also came out with a boil at my genitals which was not going away and ear infection and I was given antibiotics at the GP. I'll go and come back, and it will be the same thing. I became a little bit concerned, so I told a friend of mine who saw it and said it could be warts, have it

checked out. I realised the only place I could go to have it checked out for genital warts was the (GUM clinic), yes, it's the only place, you know; I actually came on my own, not being referred by my doctor....(Transcript 3, AW).

Siegel et al (1999) study showed that the presence of symptoms in individuals at risk of HIV and AIDS often played a greater part in the decision to seek HIV testing and medical care. They suggested that despite the presence of symptoms however, people did not immediately seek help but emphasised that the decision to a large extent depended on the interpretation of symptoms and the meaning given to them by the sufferer. Some of the participants responded to symptoms by requesting out rightly for an HIV test. However, the request for an HIV test was not always honoured by primary health care services which give the impression that primary healthcare services did not encourage testing even with suggestive symptoms and therefore missed the opportunities for diagnosis at an early stage. This is supported by literature (e.g. Burns et al 2008) which highlights opportunities for HIV diagnosis that were missed during medical encounters.

.....and I asked the docta, 'why don't you test me for HIV'? And they said 'no, you are alright'. So they said I had some gastric problem. They did all the x-rays they could do and there was nothing wrong. So in 2006, around January, I started growing sick and pale and then it came to my senses; there must be a problem, (laughs) diarrhoea, swelling things in my armpit arms, fever, gastric problems, weight loss, weak, pubic boils, loss of appetite, hair loss like Somali, rashes, sunken eyes, oral thrush, vaginal thrush...and the man [her husband] died of HIV..... (Transcript 2, AW).

Although the presence of symptoms maybe more reliable for guiding diagnosis, the importance of listening to patients requests should not be overlooked. Patients know themselves and their lifestyles better than their symptoms can tell. Burns et al (2008) highlighted opportunities for HIV screening and diagnosis that are missed at GP consultations (Chapter 2) and suggested that this could be a good starting point for offering HIV tests. The failure to explore participants' requests for an HIV test may leave the impression that primary care services are not prepared or well equipped to handle HIV and AIDS related issues.

6.2.2 Hospitalisation for Severe Illness

Nine of the participants were diagnosed during hospitalisation for severe HIV and AIDS related illnesses such as HIV and AIDS encephalopathy, toxoplasmosis and pneumonia. This stage of diagnosis was common among study participants and many of them were diagnosed with a CD4 count of less than 100 cells/mm³. For example, the following participant was diagnosed during hospitalisation for severe HIV and AIDS related illness with a CD4 count of 4cells/mm³.

... I collapsed, well, when I collapsed, I went to the hospital in the States. It's kind of mandatory that you, they rule out certain things, for instance.....they asked, would you, like to take an HIV test?.....everybody kept saying that I started to lose a lot of weight, well, ya, I had er, very cold, very... well there were changes.... in appearances. I contracted toxoplasmosis! (Transcript 9, CM).

This is consistent with findings in the literature (Erwin et al 2002, Boyd et al 2005, and Burns et al 2005). The tendency to ignore symptoms often resulted in advanced illness. Although advanced HIV illness was common among participants who failed to respond to symptoms,

its manifestations were varied and tended to depend on the specific complication with different clinical outcomes. While the above participant developed toxoplasmosis in the brain, the following developed HIV and AIDS encephalopathy with characteristics of mental illness:

.....that's what I'm saying I don't know what happened me that time. I get confused; even for me to go hospital I don't know, so one day I saw that I was in the hospital at P R [anonymous] here but, the something, at that time I think the virus, according to the doctor the virus was affecting my brain because I was behaving things; my own behaviour, but even for me to go to the starting medication or something like that. They say they take me to Park Royal here; there's a mental clinic at the other side and to NP Hospital [anonymous], so after that I start getting ok. (Transcript 8, AW).

Some of the participants were diagnosed during hospitalisation for other illnesses such as tuberculosis and recurrent episodes of severe pneumonia. For example, the following participant was diagnosed during admission to investigate severe recurrent pneumonia;

In 2006, my pneumonia led me to admission that was when I was diagnosed with HIV. It [my diagnosis] came as a shock and I was like; this I can't tell my family (Transcript 4 AW).

Associated infections in the participants were indication of advanced illness which is usually a more difficult stage to treat. While some people gave priority to their health issues, some prioritised their work. Some participants highlighted that many people migrate to the UK for economic and not health reasons and would therefore prefer to work rather than go to seek

help when they are unwell unless the illness was severe. Some literature (e.g. Ibrahim et al 2008) confirmed that for many individuals, the initial years in the UK are about meeting basic needs such as housing, financial support and securing immigration status rather than sorting out health needs. This is a possible indicator that black Africans seeking HIV treatment and care in the UK are not 'health tourists' (Gould 2008, NAT 2008) as reported in some media (e.g. Mail Online 2009).

Most people come here [England] because of the lives of people home [Africa]. All they think about is work. it's not as if they are really ill to seek treatment. Their aim of coming here is not to seek treatment. They are aware that these services are free (Transcript 5 AW).

If black man not sick, I mean not very sick he don't think of going to hospital. Black people have to go to work because they don't find job easily. And even when they have job, they've to work doubly hard to keep them jobs so unless they really sick, they don't have to go to hospital because they've to work (Transcript 30 CW).

Some people believe that black Africans and African-Caribbean people do not have the same opportunities for employment with the white British indigenes and those who are employed would prefer keeping their jobs than going about dealing with health issues that to them do not often seem serious. Furthermore, health promotion may not be a priority for this group of people. The practice of engaging with other forms of therapy such as self-care and alternative therapy may also suggest that they do not think of biomedicine as their first option.

6.2.3 Response to Health Policy

Four of the participants were diagnosed through routine testing in pregnancy, and consequently, their partners were tested. The UK Department of Health recommends that information about HIV and AIDS testing be offered to all pregnant women, and that testing be available in all antenatal clinics and should be performed following pre-test discussion with consent. This suggests that women are routinely screened for HIV and AIDS during pregnancy with the aim of giving the unborn baby a chance of being delivered HIV free. Routine HIV testing in pregnancy as health policy therefore makes it difficult for women to avoid the test when they get pregnant.

...When my wife was pregnant, when she was er, well , when they went through the tests, er all other tests, blood tests, including if you are HIV or not (during pregnancy) during pregnancy. That is when they discovered that she was HIV positive. Er when they discovered that she was positive, I was also invited in to hospital to do the test and they found that I was also HIV positive and that is how I got to come to this hospital (Transcript 27, AM).

Although some participants were screened for HIV through this pathway, two of their partners tested negative for HIV even though their wives were positive. This explains some of the complexities associated with HIV transmission which potentially impact on help-seeking.

6.2.4 Response to partner's positive HIV status

Sexual health services routinely invite the spouses of those who test positive for HIV and AIDS, for screening. Although a few participants were screened because of their spouses' positive HIV status (not during pregnancy) only one of the participants reported being diagnosed positive for HIV through this pathway.

...yes as soon as I left the clinic, the day I got my results I told my partner straight away and advised her just as the doctor told me to, invite her down here for a check-up as well (Transcript 17 CM).

It appeared that participants developed the willingness to test for HIV and AIDS once their partners had been diagnosed.

6.2.5 Health promotion and secondary prevention practice (Voluntary testing)

Four of the participants in the study were diagnosed through secondary prevention and health promotion practice. Generally secondary prevention in the context of infectious diseases refers to the early detection and prompt treatment of disease before symptoms start to manifest. Through secondary prevention, it is possible to cure a disease at an early stage and improve the quality of life of the individual. Secondary prevention in relation to HIV and AIDS refers to preventing the emergence of HIV and AIDS related infections and promoting optimal health in HIV and AIDS infected individuals. Potential benefits of secondary prevention include stopping or slowing HIV disease progression, preventing complications, limiting disability, and reducing the spread of HIV (HIV and Primary Care, 1998).

Although a few participants in this study were diagnosed through health promotion activity, most of the participants declared that they would not voluntarily test for HIV. Only two African-Caribbean men and one African-Caribbean woman effectively tested regularly for HIV and AIDS. Only one black African woman tested voluntarily once when she wanted to start a relationship.

...Cos I, I normally, come every year [to the clinic], just for a blood check-up. Sadly a year and a half ago I met this person, who I fell madly in love with, and we had unprotected sex, we both decided to have unprotected sex, and this is the thing, I didn't realise she was carrying the virus. It wasn't until we broke up I decided to come here for a test to make sure as usual, which I normally do every year, just to check on my body, that's when I was diagnosed with it....(Transcript 14, CM).

Although the above participant tested regularly, his perception of risk tended to be poor. Black Africans tend to diagnose illness based on symptoms manifested. Even at an advanced stage of illness, black Africans feel comfortable describing their symptoms rather than naming the illness. Like the above participant, the following participant practised both health promotion and secondary prevention by regularly using the condom and testing for HIV and AIDS but appeared to have poor risk perception.

Every year, like every year me used to come test me self just to live healthy, just to make sure me ok. But for the past 2yrs me too busy and me no come here to come get me self test. Me not worry to come because me always use 'boots' [condom]. Me use to go after them women but me use them boots man! So it surprise me how me come get this thing [HIV]! (Transcript 20, CM).

Health promotion and disease prevention involve a series of activities including the practice of safe sex in the case of HIV and AIDS. The above participants both practised health promotion and disease prevention but both appeared to have poor risk perception. Most of the black African participants in the study did not seem to practise health promotion or disease prevention. For instance none of them tested voluntarily for HIV. The fear of a possible positive test and consequent stigma and rejection that often accompany a positive HIV test result were some of the reasons provided by some participants for their reluctance to go for voluntary testing among black Africans. Moreover, the belief that HIV and AIDS is an ‘African thing’ can potentially result in scepticism among black Africans themselves and possibly increase the reluctance to test.

Furthermore (Chapter 2), causes of illness and the diagnosis and cure in the context of the populations studied are not only associated with biomedicine alone. The association of causes of illness by black Africans to other factors such as ancestral causes, punishment from God (Ridge et al 2008), witchcraft and taboos for example, may cause people to first of all go through the process of ancestral consultation or to spiritual powers to prevent illness or for early ‘diagnosis of impending illness’, receive spiritual healing or to go through this process accompanied by performance of sacrifices when they have signs and symptoms with the hope of preventing illness or finding a cure (Chapter 2). Leininger (1991) in her theory of Culture, Care, Diversity and Universality emphasised the importance of understanding the cultural context of the actions of individuals to be able to plan their care. Additionally, one of Blumer’s assumptions (Chapter 2) is that people react to something based on the meaning of that thing to them.

As also noted in Chapter 2, illness in the contexts of the groups studied especially black Africans is a family issue. This suggests that the healthy or the sick individual may become powerless in decisions about ‘indigenous secondary prevention’ or determining the pathway to help-seeking for diagnosis or cure as this responsibility may be taken over by any senior family member following lay consultation within the family. This is to determine the cause and significance of symptoms in ancestral terms. Moreover, the consultation of ancestors and performance of sacrifices are usually aimed at preventing illness or finding the cause of illness and appeasing the ancestors. This is done in order to remain healthy, find out the potential sources of illness, get healing (Awah 2006, Awah and Phillimore 2008) or seek God to avoid the ill luck of getting infected or becoming ill. These may be seen by black Africans as an African way of promoting health, preventing illness or seeking cure for illness, for instance, the following participant blamed God for her infection implying that disease causation is also associated with ungodly living:

I kept on just praying and cursing god. I'm like, ok what kind of a god are you? What is this then? So why er.. How is it then said that all power belongs to you, and then why are you doing this? What kind of god are you? Why did you bring me into this world when all you've done is you've put me into a family where no one else has money. I have to struggle and support everyone one else, you give me a child who is a struggle you know. I'm doing it all on my own; on top of it you give me HIV!
(Transcript 11, AW).

Health promotion practice in general even for other illnesses (such as cancer screening) other than HIV and AIDS was not welcomed by some of the participants in the study. They strongly made it clear that they would not have any form of health check even for other

illnesses. Some participants also acknowledged that it was not common practice for black people¹⁶ in general to go to hospital for routine health checks especially HIV screening.

....I have heard what people think about HIV and AIDS and other medical problems such as prostate cancer and other things, just having a basic MOT on their bodies, what I have noticed is the, the fem..., the black women , the females would have a check-up and the males won't because I have heard men say no, I don't think I need a prostate check-up, er..,er, I don't need an HIV check-up because they just believe they won't catch er...HIV because they eat right, because they keep fit and because especially if they don't see symptoms , they won't come for HIV check and out of all the illnesses in the world out there like cancer, prostate cancer, lung cancer or anything.....when it comes to the black community especially men, the last, they will not, the last thing they will do is have an HIV test because of the stigma of it and they're sort of like ignorant. (Transcript 17, CM).

This may be a cultural issue which needs to be recognised and understood by the health professional as such if they want to provide the culturally congruent care suggested by Leininger (1991).

The above quote highlights lay beliefs about HIV prevention. For instance, the participant reports that men believe that with a good diet and exercise, they are unlikely to contract HIV. These two factors are not directly linked to HIV prevention but they highlight people's beliefs about what constitutes disease prevention. Although a healthy diet and exercise are associated with health promotion, disease prevention in the context of HIV and AIDS

¹⁶ Black people in the context of this study refer to both black Africans and African-Caribbean people.

involves measures that will prevent one from contracting the illness e.g. safer sex practices such as the use of condoms and avoiding multiple sex partners. Only one black African woman in the study attempted to practise health promotion and secondary prevention by voluntarily testing for HIV and requesting to use a condom with her partner. Some of the participants in the study were not aware that it is only by testing that people can be sure of their HIV status, for instance, while the African woman mentioned above was suspicious of a positive HIV status for her partner who had risk factors for infection such as penile piercing and a tattooed body, she tested positive for HIV. It is also clear that voluntarily testing for HIV on this occasion was for the sake of her relationship and not her usual practice.

....I was dating er somebody who had piercing all over his body. I also suspected that he was gay; he's from my tribe. So erm, we would...erm risk infection, so I just wasn't very comfortable because his penis was pierced, I insisted that let's do a test [HIV] before we went any further, before we had sex! (Transcript 11, AW).

All other participants both from the African and African-Caribbean groups did not appear to practise health promotion and secondary prevention. Other reasons cited by participants to justify why black Africans and African-Caribbean people failed to seek-help to prevent HIV included shame, pride and embarrassment (Gascoigne and Whitehead 1999). Similar reasons were noted by Shilts (1987) among HIV and AIDS cases in the USA during the early years of the epidemic.

.....our embarrassment, our embarrassment erm, it takes us over, because the way we feel, shame, another race, they don't feel shame in the same respect. That is why as I

was saying, so many black men they die of cancer of the testicle because, they won't go, they think it's a shame! (Transcript 15, CW).

Black people too proud, it's pride and shame that put them off. Sometimes it's fear because them don't know what for do if them have the illness [HIV]. A black man is a black man. You cannot really convince them to go get them HIV test. Maybe when they start having some illness, (*symptoms*) symptoms, yes they can go to have test but if the symptom not serious they don't want to go (Transcript 30 CW).

Although failure to practise disease prevention and health promotion could be associated with pride and embarrassment, the main cause of such failure could potentially be fear. Moreover these opinions may stem from frustrations that may result from the difference in expectations between the health provider and the patient and because health providers may not sufficiently understand the cultural context within which health problems occur.

6.2.6 Sexual Practices

Participants in the study, who engaged with multiple partner sexual relationships, knew the importance of safe sexual practices especially using the condom. Although total protection may not completely be guaranteed some men expressed their dislike for the condom during a sexual encounter and also reported similar practice among other young people.

Some of them [young men] they don't like condoms at all, I don't like this one [the condom] I like to feel it myself, to feel natural... (Transcript 23 AM).

The failure to use a condom during a sexual encounter did not only appear to be related to the need to feel the ‘naturalness’ of the encounter but also to the optimism that the other partner did not have HIV as indicated by some of the participants.

6.3 Impediments (Barriers) to help-seeking for diagnosing HIV and AIDS

This section analyses the potential factors that hindered people from seeking help for early diagnosis with HIV. Participants' in the study identified the following factors as impediments to accessing health services for HIV and AIDS diagnosis:

6.3.1 Fear of threats to Confidentiality

Some of the participants noted threats to confidentiality as a major barrier to seeking help for diagnosing HIV and AIDS. For example, one of the participants was highly disappointed at the extent to which information about his diagnosis had been shared without his consent.

Additionally, most of the participants of both sexes from both backgrounds were concerned about keeping HIV related information and medication in their homes which could accidentally be seen by family or friends resulting in unintended disclosure. Such fears of threats to confidentiality could potentially affect the desire to seek help for diagnosis. The failure to respect patient confidentiality by health professionals and the fear of threats to confidentiality by patients were potential barriers to testing, counselling, and treatment (Burns et al 2008).

Confidentiality in healthcare has become rather complicated (Herring 2008) with professionals getting confused as to who to share patients information with and why. Healthcare professionals have to respect patient confidentiality on the basis of extensive legal, ethical and professional obligations (Health, Social Services and Public Safety 2009). The General Medical Council (GMC) and Nursing and Midwifery Council (NMC), both stress the duty of protecting patient confidentiality. This implies that a medical professional is obliged to keep personal information about a patient confidential, and is only entitled to share such information in two situations: with the patient's consent or if disclosure is in the 'public interest' (Herring 2008, General Medical Council 2009).

6.3.2 Stigma

Two forms of stigma (enacted and felt) have been identified and discussed in Chapter 2. Participants in the study suffered both forms of stigma in many different ways. While it is believed that enacted stigma results from the attitudes of the public towards HIV and AIDS patients, a greater part of stigma experienced by patients in this study appeared to come from health professionals themselves. For example the following participant was stigmatised by the attitude of health professionals.

..... Even when I went to have the mammogram done, I had to, I took issue with the doctor because she asked me if I had any underlying health problem and I said yes. I didn't hesitate to tell her that I was HIV positive but I later regretted telling her because she immediately put on my file 'black HIV positive'; ok so there is a receptionist that had already taken me to three different rooms for tests. The moment, the next time he saw me with that written on my file, his face was red, he's a white

guy, his face became red so I went back afterwards and said look, I am not happy that you have put this label on here! (Transcript, 11 AW).

Although the stigmatising attitudes that have served as some of the barriers to seeking diagnosis and control of HIV and AIDS have been blamed on the lay public, there is evidence that such attitudes are common among health professionals. Such attitudes may serve as barriers to help-seeking for diagnosis. The following participant also experienced stigmatising attitude from a health professional.

I came for an appointment and was told, ‘we just found out [that you are HIV positive], and can you wait?’ So everybody was seen before me. I didn’t understand that, because I thought everybody was treated equally regardless of their status. With all the medical reasons, that is the reason why hygienic practices are put in place so there would be no reason for me to express my status to my doctor so in the end, that was a regret and I still regret it today that my name is on file because I don’t trust that information to be held here at all. If I could change it I would. If I could advise anybody else not to give their name, I would... (Transcript 22, CM).

While universal precautions are there to protect health professionals as well as the patient, it may be inappropriate for a health professional to openly show behaviour that may be perceived by the patient as stigmatising. Such outstanding and negative attitude towards a patient by a health professional can constitute a major barrier to uptake of health services for diagnosis of illness. Other cases of stigmatising attitudes by health professionals were reflected in the way they carried out their care with patients. Although it is important to be cautious when handling infectious specimens, it is important to do it in a way that does not

make patients who are already sensitive as a result of their condition, to feel worthless. For example, the following participant was highly traumatised by the stigmatising attitudes of the staff.

Even where the health practitioners here, apart from, I mean, maybe apart from Dr B, who, he doesn't do my paper work and when I look at the file I don't see 'danger of infection'. You do a urine test and they put a huge tag on it that 'danger of infection'. That's my urine so why would you put that if it is not? (Transcript 11, AW).

While it is very clear that HIV and AIDS cannot be transmitted by touching or simply handing over an object to an HIV or AIDS patient, health professionals reinforced stigma in the patient by their attitude in providing basic care.

I called her [the nurse] first that I wanted water and she was coming like that to give me the water, you understand, just water, it was not anything, just water; I was expecting and she was coming to give me the water and then, and then, the friend called her and said oh!, I saw them talking. I don't know what they talked about and then after, she went to wear her gloves and then when she was coming to me to give me the water, it's like I have some, it's like the sickness was on my hands. I don't know whether if it touches her; I am going to give her the sickness. I felt so, so bad that day (Transcript 19 AW).

This action could have been the nurse's regular practice with every patient which she might probably consider as part of universal precautions but such precautions are encouraged in cases of real physical contact. It is also possible that if the same action involved a non-HIV or

AIDS infected individual the perception from the patient's perspective might have been different. Furthermore, one of the participants in the study was dismissed from her job because of disclosure of her HIV positive status to her employer. This can be described as institutionalised stigmatisation. The Equal Opportunities Law in employment requires employers to give employees who are HIV positive the same opportunities like non-HIV positive employees. The termination of a contract of employment based on a positive HIV status is a case of enacted stigma at institutional/organisational level and the failure to respect the equal opportunity law in employment.

.... It wasn't easy at all. I was afraid I was gonna lose my job which I did anyway (smiles painfully) but er I am hanging on. I thought I was doing the right thing [disclosing my HIV positive status] but I was shocked by their reaction. They suspended me and dismissed me later after the investigation (transcript 25CW).

Some studies (e.g. Herek 1999, Wong and Wong 2006, Infante et al 2006) have documented stigmatization in the healthcare system from health professionals themselves and this has profound impact on the decision by patients to seek help for diagnosis with HIV and AIDS. However, Evans (2001) suggested that the contribution healthcare professionals make towards stigma and perpetuate its effects is as a result of each of them being a member (and not necessarily a professional) of a society, of a social class, ethnic group, culture and of a religious group which may sometimes be stigmatising. He further suggests that becoming a health professional does not render them non-judgemental.

All the participants also experienced 'felt-stigma' and this was evident from their determination to maintain 'silences' about their HIV status even to their families. Both forms

of stigma appeared to be a major problem with all the participants although they experienced or expressed these differently. However some of the participants were determined to avoid ‘enacted stigma’ and deception was used as a way of maintaining ‘normality’.

Oh yes! She was [worried about my illness], she was and I told her that I had a kidney problem and that social worker was so good that she went into lies with me. She came home because I was so sick (laughs) and told my step daughter that, oh, well, we have got a kidney problem here. These are the symptoms; we are watching it and she will be alright within 6months. (Transcript 2, AW).

While stigma may be blamed on the need for more knowledge about HIV and AIDS as presented in Chapter 4, sexual norms cannot be ignored. HIV stigma has also been blamed on moral judgement, for instance; it is seen as a personal choice to engage in bad behaviour such as adultery and prostitution which implies that HIV and AIDS patients have to suffer because they are responsible for their illness. While it is true that some of the participants maintained ‘silences’ about their HIV status because of stigma, other reasons cited as justification for non-disclosure included job security.

It's changed me in the sense that I work with children so I have to be very careful, um, certain jobs that I could go after, I won't do it because I'm thinking oh god, you know they do blood tests and things like that and they come up. It's not everyone that is going to, you know this person might say to this one well you know so and so da da da da cos obviously if you're working in a certain situation, certain people have access to your files so therefore, they're going to, if they see something, they might think they're doing good or you know so and so has got whatever, and the next person

find it, you know it's like a child with a new toy you've got to tell everybody [...] There's certain jobs where they say have you got this, you've got to have this blood test done, you've got to have that blood test done, so it sort of limits me now, I mean I'm getting on now but it's limiting me to what I can do. What I'm capable of doing, I have to step back because I feel I'm not ready to tell people but that is the sad part of it and our people black people, oh Lord, you only have to say one thing and they go wild (Transcript 15 CW).

The above quote suggests that a positive HIV status is a limiting factor to people's capabilities. Although people may have skills for other jobs, the fear of rejecting them for employment because of their positive status indicates that their skills are not utilised and potentials remain unlocked. Pre-employment checks potentially suggest that HIV is dreaded and this is stigmatising in itself and probably sends mixed messages to people. This practice potentially causes people to maintain 'silences' about their condition and also not to seek help which has implications for the control of spread of HIV.

6.3.3 Lay Perceptions about health and illness

Participants in this study seemed to hold on to deeply rooted values and perceptions drawn from their cultural origins and therefore lived with, and drew on their cultural reality to understand health. Even with the presence of physical symptoms all the participants from both backgrounds perceived themselves as being healthy despite disease.

I don't know. I don't really know but as I am saying, I cannot take medication that I am not sick. I cannot go to the traditional medicine because I am not ill. As I say, I

stopped the medicines for some time. It is only this month I start again to take the tablets. My husband gives me support, a lot of support (Transcript 7, AW).

Black Africans appeared to define illness based on the inability to perform their daily functional role. Although the following participant had tested positive for HIV, she did not consider herself ill.

..... just because someone has HIV doesn't mean he has got full blown AIDS and I know basically for that I could just see that I was diagnosed last year and I was telling my friend there is no reason to come and visit me just to see me just because; I was diagnosed last year and I am still here and she has seen me at 2 parties and I said to her, when you saw me, what is the difference from....so (laughs) (Transcript 11 AW).

African-Caribbean women had a similar perception of illness like black African women. Although they had HIV, they did not feel that they were ill especially as some of them did not have symptoms. They understood illness in terms of symptoms.

I am not ill, I've never felt ill with it and the only problem I had at the beginning when I take, when I took the tablets it was sort of... I thought I was going to die because I took them sort of in the day time so to combat that, I take them very late at night so I sleep it off, when I get up in the morning, there's no symptoms. If I happen to forget and think oh my gosh in the middle of the night say 2 o'clock (gasps), gosh I didn't take those. Then I get up, and I take them and I have a little snack and then I go back, its fine (Transcript, 15CW).

This supports the notion of being ‘healthy despite disease’ highlighted by Blaxter (1990) in her study of lay beliefs with working class groups (Chapter 2). Some of the participants did not think that they were ill because they had no symptoms that stopped them from carrying out their functional roles. Without the feeling of being ill or the presence of symptoms, it was unlikely for black Africans and African-Caribbean people to seek help. The failure to acknowledge the presence of illness may therefore constitute a barrier to help-seeking for diagnosis.

Some participants in this study strongly held onto lay beliefs about the cause and spread of HIV and AIDS. For example the following two participants perceived HIV and AIDS as a Western invention.

They always send us injection for the sickness we er. they don't have here and he thinks they did something, some injection to send to us to get this thing because, he can't understand why they say this sickness, you can have it from sex, if you can have it from sex then everyone can have this sickness because the men, I am talking today, I have got 6 girlfriends. If I am positive the 6 girlfriends supposed to be positive and that six girlfriends if one has got 2 boyfriends and the boyfriend got 6 girlfriends, look at this thing, he said he don't believe, maybe it is one injection you receive. Maybe if you receive that injection you can have that illness (Transcript 16 AW).

Another participant attributed the cause of HIV and AIDS to contaminated food and medication sent by the West to black countries.

I remember in my country there were times when they didn't um, they didn't give the children the measles injection because they found that they actually put virus in the measles injection to send it abroad. Sometimes they can do these things and make it into powdered form; they put it into the milk. People should be aware of all these things because these are the type of things that they do. They send you batches, that batch they know where this is going, that is going and that and now in my country with the research they do not really buy meat or stuff from, um England, goes to other channels because they cannot trust what they're actually giving you. The same with me when I go out to buy food especially meat, I don't buy meat where I see a whole bunch of black people queuing up and I see the Asian man sitting in there and it's only my black, my black people. I go where, [...]. I go into that shop even if it is halal meat and it's all blacks, the answer is no. They use that meat only for one thing – destruction! (Transcript 15, CW).

Such beliefs may be detrimental not only to HIV prevention practices, but also to help-seeking for diagnosis of HIV and AIDS. These beliefs tended to be held by women in the study from both Africa and African-Caribbean backgrounds. Interestingly such beliefs were not noted among black African and African-Caribbean men in the study. So it is not clear if they had similar beliefs about HIV and AIDS causation but failed to express them or that they held entirely different beliefs about the causes and spread of HIV and AIDS.

I have seen this picture of Ethiopians; they had the famine there and they put all this to make out that we, and if you look at history, yes it's all around but the proportion of what they're saying in Africa, ninety odd per cent that's rubbish, that's a lie, the only way that can happen is that you're, you're creating that drug, and you're literally

putting it in food if we stop taking all these milk powders and go back to the natural way of breast feeding, go back to our natural herbal remedy, I think we can't go wrong, we cannot go wrong. I talk too much (giggles)...(transcript 15 CW).

The above quote suggests participant perception of some exaggeration in terms of HIV and AIDS prevalence portrayed in Africa. All these lay beliefs have a potential negative influence on help-seeking for diagnosing HIV and AIDS.

6.3.4 Barriers to Access to Health Services

The term 'access' appears simple but is a complex one. While access may be understood by many as referring to physical or geographical access, Gibbs and Lurie (2007) suggested that access comprised a variety of components among which are: geographical accessibility, financial resources, transportation, cultural consideration and competing needs. Many barriers to accessing health services may have a profound effect on help-seeking and such barriers may also include facility location, transportation, waiting times, lack of privacy in the facilities, inconvenient office hours (Aday et al 1998, Airhihenbuwa 2004). In addition to these barriers, participants in this study experienced other barriers such as lack of awareness of health services, cultural insensitivity (lack of cultural understanding), language barrier, and threats to confidentiality and immigration status. These barriers to access are analysed in greater details in the following paragraphs.

6.3.5 Facility Location

Most of the participants found the HIV and AIDS facility location a major threat to access. HIV and AIDS services were well signposted in a separate facility and participants reported experiencing 'felt-stigma' by attending the facility.

I'm thinking oh my lord, look at, [...] you know!; you come up the stairs everybody knows where you're going to, when you're pressing the buzzer to the second floor, they're thinking, you're either going to visit someone, you're either going to erm the sickle cell section or you're going to the, you're going to the HIV clinic or sexually transmitted disease clinic but straight away, my mind works every time, and when I come up those stairs, even now when I'm coming and I see loads of people, I'm thinking lord, I just hold my head up high, and I'm thinking, I'm not looking left, I'm not looking right I'm not looking centre, so imagine me at my age, you know (Transcript 15, CW).

The fear of meeting familiar people at the clinic and the separation of the different clinics constituted a barrier to access. Although the aim of having designated HIV and AIDS facility separate from other services was for improving patients' experiences, it however appeared to have a potential negative impact on help-seeking on black Africans and African-Caribbean people as it appeared to promote stigma.

Er.....would I say it's the separation and that's, you then feel it more when you are being separated. You know, that's what I felt, others would be asked to sit here and you'll be asked to go to the far end, and you say oh my God, my own case is (laughs) that's, it's, so I think it is the only thing I think; that separation. Even though I know they are trying to protect you (Transcript 3 AW).

Some of the participants emphasized that facility location as well as segregation of HIV and AIDS patients was a hindrance to access for help-seeking for black African and African-Caribbean people.

Some [people] really want to but the effect of walking in the clinic, just coming to the clinic, some really want to be tested but I think coming to the clinic here needs some amount of courage. If, maybe if the clinic was treating other things, people can feel free to come but because it is isolated, it is something else. When you are coming here, once you get on the lift and press no 2, if there is anyone on the lift they start looking at you because they think you are coming here especially when you are a black person (transcript 3, AW).

Some of the participants suggested that just mentioning the name GUM clinic was enough to prevent people from attending it to seek diagnosis. The notion of promiscuity probably comes to mind at the mention of the GUM clinic. Participants in the study did not like to be perceived as such and this probably affected help-seeking.

I think it will because er, when you mention GUM clinic to people, what they think is sexually transmitted diseases. That's what comes to their minds. If I go there people will suspect, if I go there people will suspect that I am HIV positive (laughs). So they prefer to stay away and that is when it gets bad and they are sick with other illness.
(Transcript 18 CW)

The attempts to maintain 'normality' suggested that people may not attend the clinic for testing because of the high probability of unintended disclosure. Even though people attended

the clinic for other STIs and not for HIV treatment, the clinic was generally known as an HIV clinic.

6.3.6 Awareness of HIV Services

There was an indication among participants of lack of awareness of available HIV and AIDS services. Being unaware of the availability of such services was common among participants of both backgrounds. Many of the participants only learned about the clinic where they were treated when they were referred to it. One of the participants reported that she located the sexual health clinic through the telephone directory.

This one here [the HIV clinic]? (hmm) er..I think I rang 118118, I rang 118 and asked er... for any sexual health clinic (Transcript 11, AW).

One of the participants reported accounts of lack of awareness of the availability of HIV and AIDS health services by people in the community.

Accessing the services here has not been any problem. Er, services in the community; I prepared a small questionnaire; it was about knowledge of sexual/reproductive health services. People don't know the services that are there. It's not until you are sick and diagnosed that you become aware of these services (Transcript 5AW).

Being unaware of available HIV facilities in the community may be related to lack of information about HIV in general. Moreover HIV and AIDS are some of the disease conditions that people may probably not like to identify with implying that they may not

make any efforts to know if services that deal with such conditions are available in the community unless they needed those services.

6.3.7 Information Access

Much has been discussed about information in Chapter 4 and therefore only a brief mention of it will be made here. Although all participants acknowledged having received written information from the clinic about HIV and AIDS, some of them did not feel that they had access to information because, their literacy level was probably not taken into consideration. Not everyone attending the clinic could read even though participants studied, could speak English. For instance, most of the information about HIV at the health facility appeared to be presented mostly in written form. Furthermore, there did not seem to be much information written in other languages meanwhile there were participants who spoke and read other languages such as French. This seemed to be a barrier to access as people will likely not be motivated to attend for help-seeking if they are unable to understand what is happening at the health service.

6.3.8 Cultural Incompetence

Participants in this study had diverse cultural backgrounds and it was necessary for the health professionals to be aware of these. Interaction between health professional and patients seemed to show a degree of cultural insensitivity.

The first day I came to doctor M....., she told, I was with my sister. She said “two years’ time you will died”. My sister was angry with her...say “why are you talking like that; you can call me alone er somewhere to say this, that and you don’t know what can happen like this”? (Transcript 16, AW).

Cultural practices may have a profound influence on help-seeking and this may affect care pathways (Lin et al 1982). The interplay of patient culture, clinical setting and clinician culture can pose significant challenges to the therapeutic encounter and consequently the outcome of the encounter (Lin et al 1982). For example breaking bad news such as the news of prognosis of an illness such as HIV and AIDS to a patient by the physician (as in the above case) is perceived in the African context as insensitive and even as hastening death although it is the patients right to know (Galanti 2000). In the African culture it is the norm for the family to know about such prognosis and thereafter decide how to break the news to the patient (Ayorinde 2003) if necessary.

Leininger (1991) and Papadopoulos et al (2004) have emphasized the necessity of providing cultural congruent care. Patients bring their own world views, expectations and norms to the clinical transaction and therefore highlight the need of clinicians to be sensitive to the role culture plays in a clinical interaction. Expectations about treatment influence help-seeking, discontinuation of therapy, compliance with medication and its effectiveness (Borkan et al 2000). The belief in God than in their medication by some of the participants appeared to be a cultural belief that had to be acknowledged by health professionals. Almost all black African women in the study held on to the belief that god was healing them and attributed improvements in their health condition primarily to God rather than to their medications.

There's no trace of the virus within me because I deal, I take my medication, I go for my prayer meetings that is for prayers for healing. I pray to God to help me to come out of this, so the first time I came, Dr M...told me there's no trace of the virus in my blood. I just told them 'thank God' because I've been praying to God for God to help me to be out of this problem and I know, with my medications and praying to god,

god is surely going to answer my prayers. Religion and medication do work hand in hand (Transcript 4 AW).

Some of the participants, African-Caribbean men and women as well as black African men, although they believed in other therapy and in God as a way of coping, attributed improvements in their health to their HIV medication. One of the participants pointed out that it is not his cultural orientation to come into hospital for tests.

It is very difficult for me to say what they should be doing. Obviously, my culture makes my way of life different. And it is difficult for me or other black people to come forward because of the cultural difference. [...] Yes culture plays a part (Transcript 24, AM).

As already explained in Chapter 2, beliefs about illness suggest that people may not come to hospital for testing as other culturally acceptable practices may be prioritised. It is therefore important to have a general cultural awareness of the different client groups that attend for HIV and AIDS care.

6.3.9 Clinic operation Times

The facility operation times were predominantly in the mornings with seemingly no clinics at the weekends. This implied that patients spent longer than they expected at the clinic, because of the number of patients and appointments that were fitted in within the time available. This may pose significant problems of access to people who are in employment especially those who want to keep silent about their health condition as they may have to visit the clinic regularly. A flexible appointment system where patients book convenient times of the day

may attract more patients and improve access and compliance. This may be relevant to all health care access but is of particular significance to HIV and AIDS where patients like to conceal their diagnosis and would prefer access times that are less disruptive of their work and during which they will not require time off from their employer on a regular basis.

I said, I think this place needs a lot more improvement in terms of the way, in terms of approach. I just think it could be a little bit more, more, let me say, the word is user friendly, I am not saying the staff are not being polite; I'm just saying on the basis of the way you are coming. It's like you are waiting for the bus or something (Transcript 9 CM).

Additionally, almost all the participants were worried about meeting someone at the clinic that they knew.

No, and I don't want to meet anyone from Zimbabwe or Uganda but B..... told me he is from Uganda but he is not positive, maybe. He is just doing that job (Transcript 2 AW).

The above quote suggests that people evaded the clinic for fear of unintentional disclosure. Keeping their condition confidential may be their own coping strategy and this feeling could be a potential barrier to accessing HIV health services.

6.3.10 Complementary and Alternative Therapy

As already seen in Chapter 2, the use of CAM and the belief in God are common practices among the groups studied and some of the participants did not only rely on conventional therapy but sought other forms of therapy alone or in combination with conventional therapy. Some women in the study believed that God was a vital part of their healing. Although this was a common belief among the women, this was stronger among black African than African-Caribbean women.

[...] but I hear testimonies of people who have incurable conditions and the doctors could not explain how it happened. The person himself cannot explain but only knew that, I was prayed for, I trusted god and something shifted for my sake (Transcript 3, AW).

[...] the first one would be to go to church, because I think like me, if you ask me if I ever needed treatment, I think some of them [HIV patients] also go home. I have heard of people, I don't really know any one personally but I know they go home because there are people who have been really ill, and they have gone home [Africa] and came back cured (Transcript 11 AW).

The above quotes support the belief among some participants of the effectiveness of prayer and alternative therapy in the treatment of HIV and AIDS and this potentially impacts negatively on help-seeking for its diagnosis. The belief in God for healing did not appear to be strong among most of the black African and African-Caribbean men although some African men referred to God as a source of hope. Only few black African and African-

Caribbean men believed strongly in God. All the participants had heard about traditional medicine but while most of the African-Caribbean men and women were ready to use traditional medicine if it had been researched and proven to be safe and effective against HIV and AIDS some would use it whether researched or not .

I don't know, I don't know, to be honest. I will give anything a try to get rid of this, any medicine [laughs] to get rid of this HIV from my body er I don't know, I believe, I guess I believe in traditional medicine and I want medicine (transcript 17 CM).

Although black African men also believed in traditional medicine some of them did not acknowledge their use of it with the justification of its ineffectiveness against the HIV virus.

I would say no, the reason why I say so is, traditional medicine I believe is good but for something like this [HIV], although it's a virus, I, I look at it as being a primary disease, erm it can develop into a disease if not dealt with correctly and possibly strongly, whereas if there, there's medicines which have been tested by laboratories, tried and tested and passed and what have you, licensed, I feel safer than to go with herbal remedies (Transcript 14 CM).

Past experiences with the use of traditional medicine to treat other conditions influenced some participants' eagerness to use it for treating HIV and AIDS.

Yes I believe in traditional medicine [laughs] or and the treatment I have received now, if I should compare, the thing is that I believe in traditional medicine because what happened was, when I started like, I wanted to get pregnant before and the

pregnancy was not coming so when I went to the traditional medicine home [Africa]; you see I told you I went home. When I went home I got this traditional medicine and I got pregnant so I was thinking well, is it that medicine that made me pregnant or what so I was [giggles] yeh!.. I will take traditional medicine (transcript 19 AW).

All black African women in the study believed in traditional medicine. One of the participants highlighted the impact of traditional medicine on the lives of most Africans because with the high rate of HIV and AIDS in Africa as suggested by the WHO statistics and the limited access to conventional medications, populations would have been wiped out if traditional medicine did not play a significant part in its treatment and control. There was also the suggestion that black bodies are well suited for traditional medicine and may not manifest any side effects with such medications.

I think I would research what Africans are never, because despite what WHO are saying, millions of Africans are honestly, and obviously I think the treatment would be, I think there would be some herbal remedies because it is our bodies. We've got AIDS in Africa; there would be herbs that probably do not have side effects that could be used. I would research this first before seeking medical treatment. (Transcript, 11 AW).

Some of the black African women in the study were effectively on traditional medication alongside conventional therapy and strongly believed that traditional medicine was very effective and had fewer side effects.

Oh, you know I am born in the village and I always use the traditional treatments. I can't lie to you because sometime I am not taking the medicine to the doctor because

she right, but she can't understand what is happened but I, I've got some traditional medicine who make me strong because sometime I am tired and when I am tired like this I drink and I sleep a lot. When I get up I can do everything I want. If somebody just said this, I can try. I can't lie to you I can try and it is fine. I've got some who make me strong, why not? (Transcript 16, AW).

Some of the participants were ready to use traditional medicine and prayers along with conventional therapy as long as it was indicated for HIV and AIDS.

I would [use traditional medicine] but I wouldn't stop the tablets but I would see what effects it has. Because herbal remedies can do a lot and prayers can also do a lot and God can just (wrings the fingers) change things. If you ask anything in his name I'm a Christian and I do believe very, very strongly that he will answer (Transcript, 15 CW).

Complementary and alternative therapies have the potential to delay or prevent help-seeking with illness. This may be so because people may seek alternative therapy first and would proceed to biomedical therapy when alternative medicine has failed.

6.4 Comparing the Perspectives on barriers to help-seeking to diagnose HIV and AIDS by Ethnicity and by gender

This section compares the various perspectives of black Africans and African-Caribbean people as they relate to seeking help for HIV diagnosis. It also compares these perspectives between men and women.

6.4.1 Comparing Perspectives by Ethnicity

One of the factors that deterred both groups from testing for HIV as has been seen from their own accounts is access. Perspectives on barriers to assessing health services were similar among the two groups studied. Participants from both groups found the sexual health facility a threat to their confidentiality and consequently a threat to access. The isolation of the sexual health clinics implied that anyone found there was automatically associated with HIV even though patients attended for other sexual health problems. Participants also feared meeting people at the sexual health clinic who knew them. They were aware of stigma from health professionals and some participants from both backgrounds experienced both forms of stigma. This has implications for seeking care and may potentially not only prevent people from testing voluntarily but would deter them from attending for early diagnosis when they have symptoms. Both groups also found possession of information leaflets, the presence of HIV medications in their homes a threat to confidentiality. This is likely to affect compliance as well as the ability to understand the illness. Both groups understood illness in terms of disturbing symptoms and considered themselves healthy although they had HIV.

Despite these similarities in perceptions on barriers to seeking help, they however differed in some respects. Although there was general lack of awareness of available HIV facilities, African-Caribbean participants were more aware of these services than black Africans. This is evident in the ability of some African-Caribbean participants to go for voluntary testing. Black Africans were generally unaware of services available for HIV care and were more likely to receive traditional medicine whereas African-Caribbean participants although some of them knew that traditional medicine was available were not quite keen at going for traditional medicine. They however used complementary therapy. Although both groups

believed in God, more black Africans than African-Caribbean participants believed that the belief in God could provide them a cure.

6.4.2 Comparing Perspectives by Gender

From the study more women than men held on to lay beliefs or conspiracy theories about the origin of HIV and AIDS as well as its portrayal. These lay beliefs may potentially affect help-seeking for diagnosis and care. More women than men believed in and were effectively taking CAMS. This has the potential to affect compliance. Both men and women were eager to manage information about their symptoms and to maintain normality. This implies that they delayed help-seeking and consequently, were diagnosed late. Both men and women studied had issues with physical and psychological access as explained earlier on this chapter. All perceived the segregation and isolation of HIV facilities differently from what such segregation was intended for and this had a potential negative impact on help-seeking. Both men and women were cautious about both intentional and unintentional disclosure and therefore struggled to manage information about their diagnosis in an attempt to maintain normality.

6.5 Summary

People follow different pathways to seek help for diagnosis of HIV and AIDS. However these different pathways have potential barriers from participants' perspectives which deter people to actively seek help for diagnosis. Despite the need to seek attention for the resolution of a health problem that may be suggestive of HIV and AIDS, potential barriers may include stigma, inaccessibility of HIV and AIDS services, lay beliefs about causes and

treatment of HIV and AIDS, ignorance, low risk perception, cultural misunderstanding and the availability of other forms of therapy.

6.6 Conclusion

Help-seeking behaviour to diagnose HIV and AIDS is a self-motivated activity that is influenced by many factors. These factors determine the decisions made and which pathways to follow with symptoms of illness. Although health professionals attempt to do their best in helping people infected with HIV and AIDS to feel ‘normal’ while receiving their diagnosis and treatment, they however seem to underestimate the impact of their actions on the patients’ experience of their illness and the perceptions of staff towards them which reinforces stigma. Although HIV and AIDS health facilities are separated from other services with the aim of providing the best care for HIV and AIDS patients and to improve their experience, this ironically affects access as patients feel stigmatised by this separation.

The next chapter, Chapter 7 discusses the main findings from the study. One of the main themes that emerged from the study is ‘Africanness’ and two sub-themes; ‘African thing’ and ‘African way’ are discussed in chapter 7. Three sociological concepts; silences/broken narratives, biographical disruption and biographical abruption are discussed showing how these formed a model of help-seeking for the groups studied. Some implications for professional practice are outlined and strengths, challenges and limitations of the study are highlighted. The chapter ends with suggested areas for future research.

Chapter Seven

Understanding the contrasting perspectives of HIV and AIDS infection risk and help-seeking amongst black Africans and African-Caribbean people in London

7.1 Introduction

In the era of HAART, black Africans and African-Caribbean people in the UK do not seem to be enjoying the full benefit of timely treatment of HIV and AIDS infection but little is known about why this is the case. This is mainly the result of late diagnosis, and has major consequences for the individuals, the health service and society. A successful fight against the devastating consequences of HIV and AIDS among black Africans and African-Caribbean people in the UK may be based on the understanding of the determinants of late diagnosis among the high risk black African and African-Caribbean communities. Unfortunately, those factors are still not well understood and could potentially include among others, individual, societal, cultural and health service level factors. The current study aims to improve our knowledge of some of those factors by exploring, interpreting and contrasting the help-seeking behaviours of black Africans and African-Caribbean people to diagnose HIV and AIDS in the UK, and to investigate the potential gender differences.

In exploring the help-seeking behaviours of black Africans and African-Caribbean people, insights have been drawn from four theoretical and conceptual frameworks which strengthen the emerging thesis. These include: the symbolic interactionist perspective, broken narratives/silences, biographical disruption and biographical abrupton. These theories and

concepts have been described in Chapters 2 and 3. The concepts of broken narratives/silences, biographical disruption and biographical abrupton allowed exploration of the meaning of the limitations imposed on participants by their illness with regards to help-seeking. The current chapter presents a detailed discussion of key findings from the study. A model of help seeking by these groups of people is developed and implications for professional practice are discussed. The strengths, limitations and challenges are presented and some directions for future research conclude the chapter.

7.2 Taxonomy of HIV and AIDS

“Africanness” was the main emerging theme in this study and “the African way” and “the African thing” are the key emergent sub-themes and common cultural constructions of HIV risk factors and HIV status itself by participants in this study. ‘Africanness’ is the new landscape of naming HIV risk behaviour and status without calling it by name by people of black African and non-African origins. HIV and AIDS in this study have received personalization as “the African way” and “the African thing” embroidered in ‘Africanness’. This naming provides an acceptable context for black Africans to discuss and address HIV and AIDS without fear of being stigmatised.

Claiming an HIV and AIDS status as a black African identity by black Africans and naming it ‘African thing’ is likely to be seen by advocates of stigmatisation discourse as problematic. This will be reconsidered later on in the chapter. Black Africans have identified with HIV and AIDS to the extent that they feel it is part of them. Non-black Africans, for instance African-Caribbean people also recognise it as ‘African thing’. Identifying with HIV and AIDS, can be understood from the perspective of labelling theory and could be seen as labelling theory in

action. Labelling theory is concerned with how the self-identity and behaviour of individuals may be determined or influenced by the terms used to describe or classify them. George Hebert Mead (1934) argued that people obtain labels from how others view their tendencies or behaviours and these labels cause them to adopt it as part of their identity. Frank Tannenbaum (1938), from his work with young deviants titled these tendencies ‘the dramatisation of evil’ arguing that the greater the attention placed on a label, the more likely the persons involved are to identify themselves as the label. This theory is helpful in explaining how black Africans studied perceived HIV and AIDS as their ‘thing’. Being associated with HIV and AIDS potentially places them in a situation where they are comfortable identifying themselves with it.

7.2.1 Understanding ‘the African thing’ and ‘Africanness’

The term ‘African thing’ which emerged from the study is a cultural construction of an HIV or AIDS status by participants and understood by them as pertaining to black Africans. Although, it is a complex term to fully define and understand as a result of its multiple meanings, it nevertheless provides a comfortable context for participants to talk about HIV and AIDS without fear of rejection and stigmatisation. Recognising HIV and AIDS by symptoms without naming it enables those infected to seek help for diagnosing and treating the symptoms within a cultural context without the fear of being rejected. Although they may feel comfortable claiming ownership of HIV by renaming it ‘African thing’ with the belief that it helps them avoid stigma, (because it as an ‘African thing’ it is more of a communal than an individual thing) it may potentially invoke stigmatisation.

Similarly, the notion of ‘Africanness’, originating from the study was a very prominent theme. Black Africans appeared to view themselves as victims of African attitudes and

behaviours in general, and these have collectively been termed ‘Africanness’. ‘Africanness’ not only predisposes them to HIV infection but also defines their identity as HIV victims and increases the potential for stigma among them thereby encouraging ‘silences’. HIV and AIDS were therefore seen as one of the defining elements of an African identity (Ahmad and Bradby 2008). This implies that ‘Africanness’ is associated with HIV and AIDS. Such an association is likely to portray the notion of stereotyping which is often inevitably linked to blaming of the victim. The racialisation of HIV and AIDS and their use as a defining element of African identity is not a new phenomenon in epidemiological and socio-cultural portrayals of health and illness (Ahmad and Bradby 2008) where a biomedical breakthrough proves challenging. Some ethnic populations have also been identified with illnesses through a similar process (Ahmad and Bradby 2008).

In the present multicultural arena in which the UK finds itself, it is worth considering other cultural landscapes inherent in the different emerging main ethnic groups when setting an agenda for disease and illness prevention. The taxonomy used by study participants to address HIV and AIDS fails to recognise the dominance of the medical approach to address it by depriving it of its required biomedical meaning as a disease caused by a virus rather to one caused by cultural and other non-biomedical factors. This can better be understood through the ‘lens’ of symbolic interactionism which holds that people act on the basis of the meaning that things have for them and that meaning is derived through interaction with others or with the self.

From the literature it is noted that western cultures hold a ‘naturalistic paradigm’ of disease, that is, they tend to attribute illness to the individual or to natural causes whereas individuals from non-western cultures tend to hold a ‘personalistic paradigm’ of disease, that is, they are

more likely to explain illness as a result of social and supernatural causes (Foster 1976, Furham et al 1999, Kottak 2008). Literature has identified that in non-western cultures the biomedical model does not predominate and that illnesses that are believed to be supernaturally caused are best treated by supernatural means. The dominance of the medical model in western cultures may perhaps cause health professionals to overlook alternative or complementary therapy as relevant to people of non-western cultures. The groups studied addressed HIV the way they understood it. HIV and AIDS was understood by them in many different ways as noted in Chapter 4 (as African thing, as an outcome of prostitution, as an outcome of carelessness, as chronic illness, as leprosy, as punishment from God, as a death sentence and HIV as AIDS). All these perceptions either carried an element of blame, fear or negative connotation (Nyblade et al 2003) and these are potential barriers to seeking biomedical help. More importantly, seeking biomedical help requires a process of questioning, legitimising and naming the illness before initiating treatment and this invokes the feeling of loss of dignity (as one of the participants stated) and the feelings of a sense of invasion.

The absence of this process in self-care and in the traditional (non- biomedical) model is likely to make people comfortable seeking these sources for help rather than biomedicine. Believing that people are diagnosed with advanced illness because they seek help late potentially reinforces the dominance of the medical model without the consideration that non- biomedical sources of help are equally important. Siegel et al (1999) study outlines the importance of symptoms in decisions about help-seeking. Irrespective of whether they seek biomedicine, CAM or carryout self-care, the symptom is the key player and where they eventually end up is dictated by the severity of symptoms and their response to the various treatment options tried.

The groups also understood the causes of HIV in terms of conspiracy theories reflecting in their belief that HIV and AIDS among the groups studied was a western laboratory invention. These types of perceptions are what they consider as the real causes of HIV and AIDS, explaining the divergent views in help-seeking. Switching back to nature and discarding the current trend of treating illness and diseases explains the covert intentions and real habits of unsafe sexual habits and delays in seeking help. Such perceptions are likely to instil in them the tendency to distrust the biomedical approach to help-seeking and they are therefore likely to take alternative action or to take no action at all with resultant late diagnosis.

Furthermore, participants' understanding of HIV and AIDS as a chronic illness can be understood from the perspective of Bury's biographical disruption (Bury 1982) and offers an explanation to seeking help late for HIV diagnosis. Biographical disruption lays emphases on the disruptions caused by chronic illness in everyday life such as disruptions in personal expectations, plans and structures that require the individual to think about his/her biography and self-concept. Seeing through the 'lens' of Bury's concept people with HIV and AIDS experience biographical disruption and as Bury puts it 'face the worlds of pain and suffering' (1982, 169).

Within Bury's concept such worlds create dependency on others for satisfaction of many needs and this is likely to result in the loss of social networks such as family and friends with consequent isolation. Attempts to avoid isolation suggest that people infected with HIV and AIDS do all that is possible, to appear normal despite all the potential or actual disruptions imposed on them by their illness. The difficulties in maintaining normality as a result of the plethora of symptoms that start to/or continue to appear as the disease progresses suggest that some of them begin to falsify their suspected or actual diagnosis in their narratives, that they

decide to keep silent or limit disclosure to a few people and avoid HIV and AIDS health facilities and health information and that they begin to describe their symptoms. A disrupted biography was described by participants in terms of their inability to form long lasting relationships such as marriage, to make future plans for themselves as they were not sure how long or how far their illness career would take them or to get profitable employment in the areas of their expertise.

Attempts to maintain normality by the groups studied despite all the disruptions imposed on their biography by the illness is an important phase of their illness experience which they continue to hold onto until all alternatives are exhausted. This is the stage where death is eminent and Locock et al (2009) have described the feeling of impending death or uncertain future as biographical abrupton. At this point there are two alternatives which include seeking help for diagnosis and care or facing eminent death from opportunistic infections and complications. It is at this stage that seeking help is no longer a choice but obligatory if the individual anticipates survival.

7.3 Challenges to using biomedical technologies by black African and African-Caribbean groups

The determinants of help-seeking for diagnosis identified in the study reside mainly in cultural factors. Different cultures have their own belief systems and attributions about health and illness (Vaughn et al 2009) and these systems and attributions underpin their help-seeking behaviours to diagnose and treat illness. As seen from the literature (Snow 1974, Chipfakacha 1994, Awah and Phillimore 2008, Nayak et al 2012), cultural beliefs and practices about illness are associated with factors, some of which include ancestral factors,

taboos and witchcraft. These beliefs become major determinants of decisions about care especially for illnesses that have no cure like HIV and AIDS without immediate thoughts about other causative factors such as biological factors. Some of such factors were key determinants in decisions around seeking help for HIV and AIDS diagnosis among black Africans in particular and to a lesser extent among African-Caribbean people. Therefore, to understand how people react to illness, it is important to understand their cultural orientation (Papadopoulos et al 2004, Helman 2007). From a symbolic interactionist perspective, their cultural orientation provides meaning to the symptoms of the unknown illness which is understood by them as an illness which has no specific name. As such the choice of care they seek is based on the meaning they attribute to these symptoms.

The emphasis placed by western cultures on biomedicine to diagnose and treat illness fails to recognise cultural beliefs of other people around illness causation and treatment (Bury 1997). This emphasis implies that the impact of illness on individuals is not considered holistically. As such biomedicine thrives at the expense of cultural approaches to diagnoses and management of illnesses. Western cultures rely mainly on the biomedical approach to tackle symptoms of illness, (because this approach is grounded in their culture with limited alternatives); but black Africans and African-Caribbean people may seek, in addition to biomedicine, alternative approaches more grounded in their cultures. For example, black Africans may adopt an ethno-medical approach to tackling symptoms of illness while African-Caribbean people may adopt a symptomatic self-medication approach. These may be grounded on the cultural context of medical options where they live and that which they have acquired. Moreover, HIV in the black African context is a foreign illness without an indigenous African name for it (Awah et al 2009). Such an illness is described in terms of symptoms and cultural attributes and treated as such (symptomatically and culturally) before

reaching the biomedical scenery when symptoms fail to resolve and when they begin to ascribe meanings of biomedicine to illness entities and symptoms. From a symbolic interactionist perspective, illness in the context of the groups studied can be described as understood and managed through social interaction and cultural routines (Biddle et al 2007).

There is evidence that other ethnic groups are similar to the groups studied in their help-seeking behaviour. For example, HIV positive or at risk South Asians delayed biomedical help-seeking until after they had sought traditional healing methods such as herbal medicines, fasting, visits to religious healers before resorting to western biomedical treatment (Eisenberg et al 1998). However, their delay in seeking western medical care, in addition to fear of stigma was related to lack of availability, affordability, accessibility, language barriers, financial difficulties, immigration status and lack of acculturation (Bhattacharya 1994). Unlike black Africans and black African-Caribbean people studied, there is also evidence that South Asians have the illness belief that life events are beyond an individual's control and thus may tolerate undesired events as destinies they must accept. For this reason they may endure health problems rather than seek timely healthcare to avert them (McLaughlin and Braun 1998).

7.4 Locating Complementary and Alternative Medicine in the course of help-seeking

The current study has demonstrated the importance the groups of people studied place on complementary and alternative medicine (CAM) and has shown how these healthcare approaches constitute a major part of their health care sources. The NHS in the UK is free to all at the point of access, but the preference for CAM (which may not be free at the point of

access) by these groups implies that the choice of such approaches is not socio-economically determined. Although there is awareness of the western biomedical system and the effectiveness of HAART, there is still a tendency to prefer CAM sources. What CAM sources mean to them is that, not only is there no legitimisation and naming of the disease (that could consequently result in stigmatisation) by CAM sources but such therapies are presumed to be effective and have no side effects (Sweet 2011). Attribution theory also plays a part in the preference for CAM; the course of action chosen depends on the perceived causal explanation. However the popularity of CAM is not new in chronic illnesses. Its use in some countries like Germany supports its legitimacy. Its use in the management of cancer confirms its recognition in chronic illness. Schraub (2000) highlighted the use of many forms of questionable or unproven treatment methods for cancer treatment all over the world. These choices may be related to social and cultural factors and with severe illness there is the motivation to exploit all avenues to find a cure and unproven methods are therefore exploited (Pal 2003).

In developed countries, exploitation of complementary therapy is adjunct to mainstream care in management of symptoms (Vickers and Casileth 2001) whereas in many developing countries the use of such therapy is a treatment option in itself (and not adjunct) with more complex and multiple factors (e.g. ignorance, socioeconomic factor, inadequate access (Pal 2003) and culture) acting as the driving force behind their use. For better compliance with biomedical regimens by black African and African-Caribbean people with HIV infection it may be necessary to acknowledge and perhaps integrate CAM regimens in HIV and AIDS prevention and care.

7.5 Disclosure

One of the factors from the study that impedes help-seeking is disclosure. Disclosure appeared to have a major part to play in seeking biomedical help. For HIV and AIDS to be legitimised and named, there has to be a significant amount of disclosure i.e. to the doctors, the nurses, the health advisers, the laboratory technicians, the pharmacist, the receptionists and many other members of the multidisciplinary team. Furthermore, the potential for unintentional disclosure is high by virtue of other patients waiting for their appointments and who may not like to be seen by anyone outside their treating team. The fear of disclosure (both intentional and unintentional) was a common theme among all participants studied. Seeking biomedical help implied that they had to be ready to have their symptoms legitimised and their diagnosis confirmed through laboratory examination.

Seeking biomedical help renders them powerless in controlling/managing information about their illness and this is likely to increase their inability to maintain a state of ‘normality’. A better option for them where they will still be able to maintain a public and a private self-postulated by Goffman (1959) and where their perceived state of ‘normality’ will not be jeopardised is to either self-medicate or to attend for alternative therapy where the probability of intentional and unintentional disclosure is minimised. The fear of disclosure can be illuminated by consideration of the concept of broken narrative. As stated in the literature, Drakos (2008) describes broken narratives as the way people feel prevented to talk about their own or relative’s illness. He described broken narratives/silences both as a daily practice whereby individuals try to take control of disclosure of their diagnosis as a means of staying ‘normal’ and avoiding the stigmatising consequences of disclosure to family and friends. He also described broken narratives/silences as embodied practice, whereby silences is described

in two ways; as a form of suffering as well as a way of avoiding suffering. Therefore, the importance the participants placed on ‘normality’ makes alternative sources of help-seeking other than biomedicine the likely valued options.

7.6 Cultural competence

The study revealed gaps in cultural competence among health professionals and this constituted a barrier to seeking help within the biomedical system. The emphasis on cultural diversity in the NHS suggests that cultural diversity is becoming more visible, with an increase in the range of different cultures in the UK and health professionals required to meet the needs of diverse cultural groups (Papadopoulos et al 2004). Leininger (1991) suggested that sharing a cultural identity requires knowledge of trans-cultural nursing concepts and principles. Although the workforce in the NHS today is culturally diverse, the tendency of minority ethnic staff to become ‘westernised’ has made cultural expectations from patients’ perspectives not to be sufficiently met leaving them feeling that they are expected to adhere to local cultural norms.

The traditional models of acculturation assume that people take on the values, customs and language of a new culture, and are expected to drop the values, customs and language of their old culture (Berry 1997) but this is contrary to Leininger’s (1991) theory which holds that it is the duty of health professionals to have knowledge of diverse cultures in order to be able to provide culturally congruent care. Berry (1997, 2001) suggested that individuals or groups of people develop one of four strategies to acculturation which he groups into two dimensions. According to Berry, individuals or groups respond to acculturation by either maintaining their heritage, culture and identity thereby ignoring the host culture or they seek relations among

both dominant and non-dominant groups. The four strategies identified by Berry include: to maintain their original culture but interact regularly with the host culture, maintain cultural identity and avoid interaction with host culture, assimilate and forget own culture, do not maintain cultural identity and show very little interest in dominant culture. However, the socio-cultural context of the host society plays a major part in the strategy assumed by individuals. Britain has been noted for having an assimilationist attitude which assumes that immigrants would not only adopt all aspects of British life but also speak English as their first language (Ahmad and Bradby 2008). The multicultural nature of Britain suggests that health professionals have to be aware of the impact of different cultures on the way patients go about their illness and consequently the need for cultural understanding of illness entities.

The process of migration has seen an increase in racial segregation (Massey and Denton 1993, Yinger 1995), a process by which people of similar race and culture settle together. This implies that they still effectively live within their cultural practices without scope for learning new cultures. While ‘foreigners’ like black Africans and African-Caribbean people are expected to assume their new culture (the British culture), health professionals on the other hand are expected to have a basic cultural understanding of their patient populations’ background cultures (Papadopoulos et al 2004). The multicultural nature of the UK is a challenge and makes it difficult for health professionals to assimilate all these different cultures to act in appropriate ways acceptable to the different cultures or to provide specific culturally congruent care. The adherence to traditional black African remedies or to self-medication with apparent less interest in biomedical regimens in the UK by some of the HIV positive black African and African-Caribbean participants respectively reflects the challenges posed by failure to adjust to a new culture and cultural incompetence by patients and health

professionals respectively, which as a consequence are likely to affect help-seeking and compliance.

Cultural expectations did not appear to be met although the clinics comprised staff of diverse ethnic origins that may have been in a better position to understand the ethnic diversity of the participants and consequently their cultural orientations and beliefs. Given the diverse nature of the NHS workforce, cultural matching of patients and health professional is possible but is likely to be a complex issue (Ayonrinde 2003) as a result of potential differences between patient and health professional especially in social statuses that may complicate the therapeutic relationship. Staff from African and African-Caribbean backgrounds may not necessarily be the solution in trying to ensure cultural competence when dealing with the respective groups. This is evident from my experience as a black African, of interviewing participants of black African background, during which one of them who had agreed to participate in the study was subsequently withdrawn from it after he became uncomfortable as soon as he discovered our common culture. Language, even when shared, does not ensure skilful clinician–patient communication as there are different culture codes for interpersonal relationships, disclosure, privacy, and non-verbal communication (Kleinman et al 1978).

The issue of cultural misunderstanding by health professionals is likely to cause tension between the health professional and patients and this may invoke feelings of stereotyping among the patients, misunderstanding of their needs by health professionals and consequent misinterpretation of health messages by the patients. Adherence to indigenous cultural practices and the apparent cultural incompetence of the host NHS organisation suggest that people will not be eager to screen for HIV and AIDS. This implies that people will be diagnosed at later stages of illness as they are not able to attend for screening for HIV and

AIDS given the many perceived hindrances around them. Given that the majority of patients attending the clinics for HIV and AIDS care are black Africans who tend to behave in similar ways as demonstrated by the study, it may be necessary for health professionals to pay particular attention to the black African culture and involve them as much as possible in designing their care.

7.7 Reconstructing the UK health provision to integrate HIV and AIDS services in healthcare facilities

Despite the availability of HIV and AIDS health facilities, the apparent ease of access to these facilities and the availability of HAART, physical and psychological access to HIV and AIDS care remain problematic. The isolation/segregation of sexual health facilities suggests that black Africans and African-Caribbean people are likely to feel uncomfortable when they attend and would probably do so as a last resort. The preference by most of the participants for a facility that catered for the needs of everyone and not only people with sexual health problems which does not make it obvious that anyone going in there has HIV and AIDS infections is a farfetched option in this case.

Sexual health facilities were isolated and those for HIV and AIDS were segregated. The segregation of such facilities is unlikely to diffuse the message that HIV and AIDS are a chronic illness. Although this is understood by health professionals in terms of providing a better experience for HIV patients, the patients on the other hand are likely to interpret the aim of this segregation differently. A significant number of black Africans and African-Caribbean people continue to perceive HIV and AIDS as a terminal illness (biographical abruption), and such segregation may be interpreted negatively to mean that they pose a

danger to others who attend for other treatments. Rather, this practice has the potential to increase stigma and makes testing for HIV to appear an abnormal process. This implies that black African and African-Caribbean people may find it difficult to access the health facility or to test voluntarily for HIV as a health promotion strategy or to test for HIV in response to symptoms. However there can be potential for assimilation of HIV and AIDS preventative measures through a normalisation process which may require that HIV and AIDS patients are cared for in the same facility with people who attend for other treatments.

7.8 Constructed images and evolving identities

Many participants defined their biography in terms similar to Locock et al's (2009) case of the MND as they described their diagnosis in terms of the feelings of a death sentence. Inadequate information about HIV and AIDS and participants' inability to differentiate between HIV and AIDS resulted in uncertainties about the outcome of their illness. Many black Africans and African-Caribbean people with HIV and AIDS see their life as meaningless and short and consequently do not see the need to seek health care until a time when symptoms can no longer be contained. Many of the participants had not attempted to reformulate their life goals to accept and incorporate HIV. Incorporating HIV into their life goals could have allowed them to discover the different opportunities available to them and to give their lives new meaning (Doyal and Anderson 2005, Baumgartner 2009). This means constructing HIV and AIDS within the framework of biomedicine.

7.9 The Implications of claiming an HIV Identity through ‘African thing’

As noted earlier on in the chapter, claiming that HIV and AIDS is an ‘African thing’ by black Africans and non-Africans, is likely to be seen by ‘outsiders¹⁷’ as stereotyping. HIV and AIDS stigma has been documented throughout the world but this seems to be particularly common in black Africans (Miller et al 2007, Greeff et al 2008). Not only does HIV engender rejection, prejudice and consequently stigma, it is a great source of fear implying that those living with HIV and AIDS will find any strategy to cope or to appear ‘normal’. One of the ways that HIV and AIDS patients including black Africans do this is that they go through the process of denial and silence (Rankin et al 2005) in an attempt to portray an outward appearance of ‘normality’ and this can be described in terms of a desperate attempt to avoid the stigma that HIV and AIDS engender. Claiming an HIV identity under ‘the umbrella’ of ‘African thing’, can be understood as an adjustment mechanism aimed at protecting the self from enacted stigma and often results in thoughts or behaviours that portray ‘normality’ such as the refusal or reluctance to disclose a positive HIV status.

Furthermore, as noted in the literature, black Africans tend to move with their cultures. In Africa there is no culturally accepted name for HIV (Awah 2009) resulting in HIV and AIDS being known by its attributes or described only by symptoms and not by name. These attributes are understood by black Africans, and as long as HIV and AIDS are described as such without the name HIV and AIDS ascribed to these symptoms or attributes, stigma remains farfetched. Major illnesses in Africa have indigenous names but the case of HIV is different. Describing HIV and AIDS and not calling it by name in Africa is not because black

¹⁷ Outsiders as used in this context here, refers to non-Africans and those who have no understanding of the African cultures.

Africans are unaware of HIV and AIDS but it is possibly a way of downplaying its severity and impact and attempting to avoid the stigma that is immediately engendered when the name HIV or AIDS is pronounced. To illustrate the unacceptability associated with the disease, Greeff et al (2008), Wood et al (2008), Duffy (2005), Muula and Mfutso-Bengo (2005) noted that in Africa, terms such as “a long illness” or “a short illness” are used in the obituary of someone who dies from HIV and AIDS rather than mentioning HIV and AIDS which is the real cause of death. These descriptions are used because they are deemed culturally acceptable. Campbell et al (2007), Uys et al (2005), Chimwaza and Watkins (2004) also noted the reluctance to mention the name “AIDS” while the illness is ongoing thereby leaving the community unsure of the actual illness. This process can be a way of denying HIV and AIDS or simple avoidance of explicitness or specificity as a way of coping with the serious threat of HIV and AIDS (Uys et al 2005, Campbell et al 2007, Greeff et al 2008, Wood and Lambert 2008) and the repercussions.

Similar to the process of describing HIV related obituaries in terms of ‘protracted or brief illness’ rather than specifying it as death from HIV and AIDS, black Africans and African-Caribbean people studied referred to HIV and AIDS as ‘African thing’. By referring to it as ‘African thing’, the stigmatizing effect is likely to be minimized. Moreover, referring to HIV and AIDS as ‘African thing’, is more of a communal than an individual issue. This is likely to attenuate its stigmatizing impact as they feel that there are many of them in the ‘same boat’. To them this is a collective identity and therefore the effect is likely to be less stigmatizing than if it was an individual identity. Advocates of stigmatization discourse are likely to see this through a different lens from black Africans themselves who see this claim as a way of avoiding stigma rather than in terms of engendering stereotypes.

7.10 Usefulness of broken narratives, biographical disruption and biographical abrupton

The concepts of broken narratives/silences (Drakos 2008), biographical disruption (Bury 1982) and biographical abrupton (Locock et al 2009) provide a platform to understand the pathways to help-seeking for diagnosing HIV and AIDS by black African and African-Caribbean people. Broken narratives or silences, although they enable coping with the onset of symptoms of HIV, constitute a lonely and confidential phase of the illness experience which mirrors the biomedical phase of help-seeking. This is an individual experience in biomedical terms. Although this phase may help to maintain a temporal sense of normality within the individual during which they are able to manage the self by engaging in self-care activities, it does not reflect the typical cultural approach observed within the black African and African-Caribbean cultures which is of a family or community nature. Drakos (2008) described silences as an everyday practice which can separate different realities. Irrespective of whether the cause of HIV is understood from a biomedical reality or from a cultural reality, broken narratives/silences remains an important experience of this phase of ‘normality’. Drakos (2008) further described broken narratives/silences as embodied practices whereby broken narratives/silences serve a dual role – a means of suffering and a means of avoiding suffering. Drakos (2008:107) pointed out that

‘while many people with HIV and their relatives find a good balance in deciding in consensus whom they will confide in and whom they will not inform, and do not find this particularly difficult, others can feel that the demand to observe silence is an enforced and frustrating burden’.

According to him, if HIV and AIDS are able to give rise to social stigmatisation, the silences about the disease can be both indicators of suffering and instrumental means to avoid suffering and asserting power of sustenance.

Biographical disruption has a greater potential to bring the HIV infected individual closer to a form of therapy as a result of the plethora of symptoms that begin to inhibit normal functionality. During this phase in the context of Bury's (1982) concept, the individual's plans and expectations, such as, securing employment, starting a family are disrupted as well as the structures of everyday life. Bury (1982:169) suggested that this phase requires 'a fundamental rethinking of the person's biography and self-concept'. Although there is an actual or potential experience of the 'the worlds of pain' and suffering, with increased dependency on others and loss of social networks, such as, families and friends with consequent isolation, the sick individual still struggles to remain normal despite the disruptions imposed on their biography by HIV and associated infections. Charmaz's (1983) similar work on chronic illness explained clearly why people with chronic illnesses lived restricted lives. One thing she made clear is that apart from the physical difficulties imposed by the illness that made maintenance of former activities difficult, people with chronic illness do not want to be seen in their altered state. This stage (of biographical disruption) is important as it initiates the process of lay consultations with involvement of the family and provoking the need for ancestral consultation and initiation of alternative therapy. As long as the illness is described in terms of symptoms and not the name, it is more meaningful to the patient and family and is treated as a family issue as they are comfortable dealing with the symptoms of an unknown illness and not HIV in their cultural context.

Biographical abruption represents the end phase during which the individual is overwhelmed by impending death at which point they engage with the health service where biomedicine names and legitimises the illness through laboratory tests and interpretation of symptoms. They face great uncertainty about the trajectory of their illness at this point. While some of the patients are unsure if they would tolerate the highly toxic antiretroviral medications, some are doubtful of its effectiveness. People will seek help for HIV and AIDS as the ‘African thing’ because it is more acceptable to them. The three concepts are therefore very significant in explaining the initiation and maintenance of a help-seeking pathway for diagnosis of HIV and AIDS and have formed a model of help-seeking by these groups of people (Fig 3).

Help-seeking is therefore a major part of illness behaviour (Mechanic 1968) and represents only one of the many alternatives employed by individuals to respond to illness. It can be seen as part of a broader socially embedded illness career from a sociological perspective (Biddle et al 2007). Other responses to illness include self-care and attempts to cope or accommodate symptoms to remain ‘normal’ (Dingwall 1976, Pescosolido 1991) as depicted in the model. Illness behaviour is not a simple decision about professional help-seeking but a multi-faceted, protracted ‘career’ composed of a plurality of strategies and people consulted during the process of coping with symptoms (Biddle et al 2007). These interlinks are summarised into a model of help-seeking on Fig.3 below. What biomedicine considers normal is for individuals to live a healthy life and avoid risk behaviours. Biomedicine also requires that individuals especially those who are at risk should test voluntarily for HIV and to start treatment early if they test positive. Biomedicine considers alternative medicine as unscientific (Pool 1994, Helman 2007) and only delays the process undertaken to seek appropriate healthcare. Implications of the findings for professional practice are drawn out in a later section in this chapter.

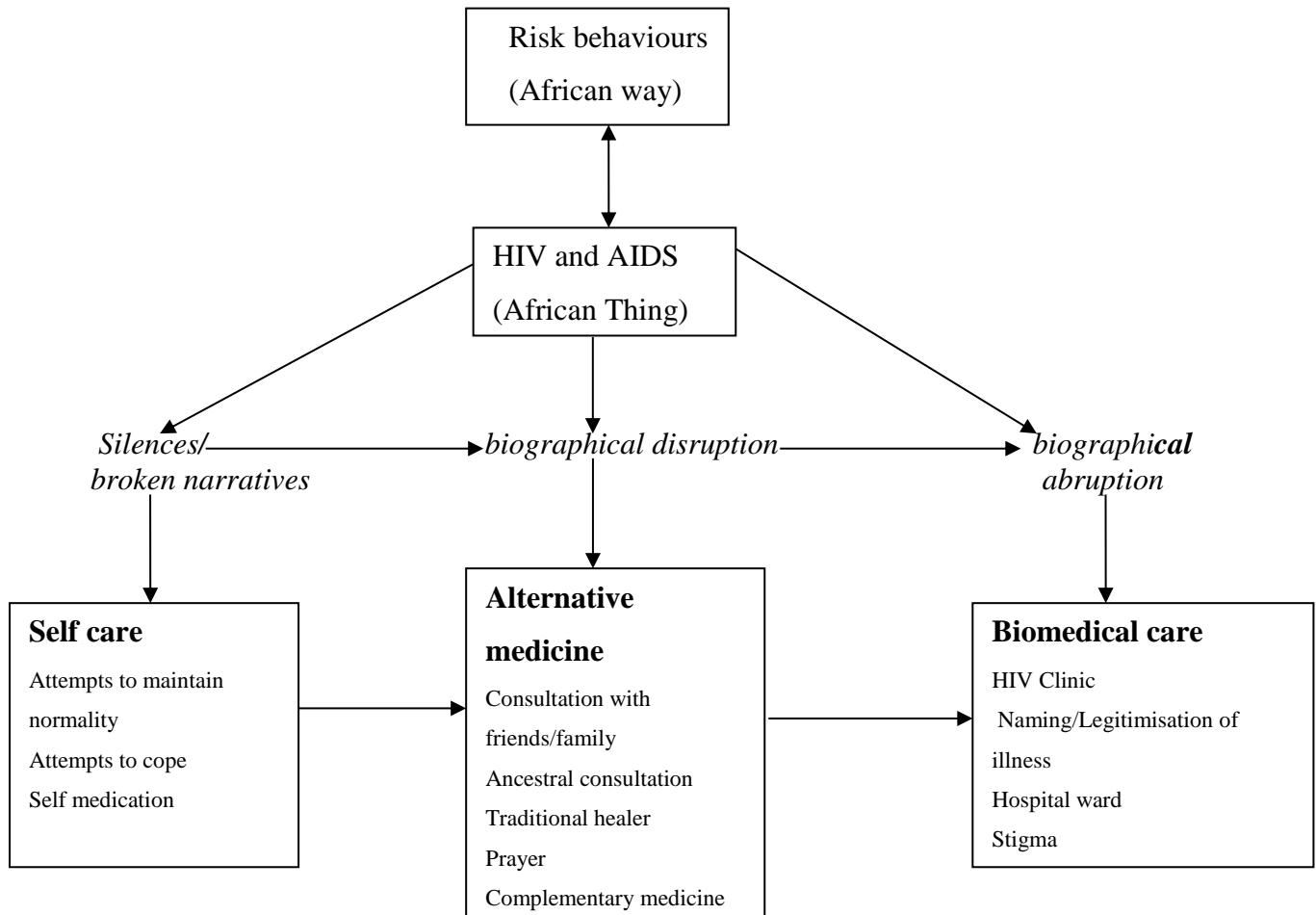


Figure 3: A model of help-seeking with the HIV and AIDS

7.11 Comparing the help-seeking behaviours of black Africans and African-Caribbean People

The findings from this study have demonstrated similarities and differences among the two groups in terms of seeking diagnosis for HIV and AIDS. The study also provided an understanding of the common problems faced by these two groups of people in attempting to

seek diagnosis for HIV and AIDS in London. Participants' narratives highlighted the conflicts they face as HIV patients and the complexities in trying to live a normal life despite enacted and felt-stigma and their disrupted biographies. The following sections summarise key similarities and differences.

7.11.1 Similarities in help-seeking

Evidence from the current study illustrates that participants from both groups tended to seek help for diagnosis later on in the course of their illness. However, the reasons for diagnosis at later stages of the disease from the perspective of both groups demonstrated some differences, an aspect which has not been explored by previous studies. Black Africans tended to delay help-seeking because of the belief that their illness was as a result of other causes other than biomedical causes and would best be managed indigenously and thus start off their search for a cure with self-care and alternative therapy before seeking biomedical care.

African-Caribbean people on their part also tended to seek help for diagnosis at a later stage of their illness after trying out prayer and self-medication to treat symptoms before turning to biomedicine to seek help. Lay diagnosis plays a key part in the early stages of the disease among both groups during which symptoms to them may not really point to a specific illness. However, with black Africans in particular, this is the initial and crucial phase of help-seeking which may be complicated by attempts of normalisation through silences or broken narratives, denial and consequently delays in seeking help (Mechanic 1968, Freidson 1970, Zola 1975, Dingwall 1976). African-Caribbean people on their part also go through a phase of denial complicated by silences in an attempt to maintain normality but clinging on to prayers and self-medication and thus delaying help-seeking. This practice by both groups is

likely influenced by gaps in knowledge and cultural influences. The fear of disclosure may also be blamed for this and the great desire by both groups to be seen as normal despite disease.

Both groups showed some variation in knowledge but generally all the participants manifested and expressed gaps in knowledge related to HIV and AIDS. For instance, all participants from both backgrounds were unaware that HIV was different from AIDS and most perceived HIV and AIDS as a death sentence. Additionally, all participants had received information about HIV and AIDS at the clinic although they felt that the information was insufficient but all of them were uneasy with leaflets as the main source of information justifying their unease to the high potential of unintended disclosure. Although they had all received information at the clinic about HIV and AIDS, both groups appeared to show less interest in understanding the information. What appeared to be a priority to them at this point was to maintain ‘normality’ by controlling disclosure.

Both groups were actively involved with multiple partner relationships. Multiple partner relationships in the black African context are not really viewed as risk behaviour by black Africans since the black African culture permits and legalises such relationships. This practice is very much ‘alive’ among African-Caribbean people even though it is not accepted and legalised. Such behaviour among both groups is the likely culprit for the increasing rates of infections among these two groups. Both groups had a rising rate of HIV and AIDS infection among them but both still perceived HIV and AIDS as an ‘African thing’ rather than a disease that is likely to affect anyone involved in risky sexual behaviour. This is interesting as it does appear that African-Caribbean people may be under-estimating the degree of infections among African-Caribbean people.

Perspectives on barriers to assessing health services were similar among the two groups studied. Participants from both groups found the location of the sexual health facility a threat to their confidentiality and consequently it posed a potential threat to access. The isolation of the sexual health clinics implied that anyone found going in that direction was automatically associated with HIV even though patients attended for other sexual health problems.

Participants from both groups were aware of stigma from health professionals and some from both backgrounds experienced both forms of stigma. This has implications for seeking care and may potentially not only prevent people from testing voluntarily but would deter them from attending for early diagnosis when they have symptoms. Participants from both groups also found possession of information leaflets, the presence of HIV medications in their homes a threat to confidentiality. This had a high likelihood to affect help-seeking and compliance to treatment among both groups and the ability to understand their illness. Both groups understood illness in terms of disturbing symptoms and considered themselves healthy although they had HIV.

7.11.2 Differences in help seeking behaviours

Despite these similarities in help-seeking behaviour among the two groups, they however differed in some respects. Although there was general lack of awareness of available HIV facilities, African-Caribbean people were more aware of these services than black Africans. It is likely that awareness of the availability of such services was not important to black Africans. As already discussed earlier, black Africans were more likely to treat their symptoms from a non-biomedical perspective. Additionally, they responded to illness by tackling symptoms and not naming the illness. This implied that they did not have the need

for sexual health services since their illness, which had no name to them was not necessarily HIV and therefore being aware of their availability was not important to them.

African-Caribbean people on the other hand were more aware of such facilities because they were more likely to understand their symptoms as HIV and not just as an unnamed illness. Although they sought help later, their reason was related to managing disclosure and not because they were not aware that their symptoms could be HIV. The African-Caribbean group was more aware of the importance of disease prevention by seeking out for voluntary testing than black Africans. The way black Africans prevent illness is by going through ancestral consultation rather than voluntary testing highlighting the importance they place on cultural approaches to preventing and managing illness than biomedicine.

African-Caribbean people were more open about their sexual practices and even about their multiple partner relationships although such relationships are not permitted in the Caribbean but black Africans on the other hand did not talk about multiple partner relationships or polygamy even though it is legalised in the African society. Having multiple partner relationships was normal to black Africans and talking about them would have been ‘labouring the obvious’. African-Caribbean people talked about such relationships because it was not normal practice expected of them.

7.12 Comparing help-seeking behaviour of men and women

The current study showed some similarities and differences in help seeking behaviour between men and women and these are presented in the following section. From the literature, there is some controversy about help seeking differences between men and women

with some studies (e.g. Green and Pope 1999, Boros et al 2000, Bertakis et al 2000) suggesting that women seek help more than men and others (e.g. Feeney et al 1999, Macintyre et al 1999, Elmslie et al 1999, Gijsbers Van Wijk et al 1999) noting that there are no difference in help-seeking between men and women. Findings from the current study however showed minor variations in health behaviours and help-seeking between men and women which supports the work of Green and Pope (1999), Boros et al (2000) and others.

7.12.1 Similarities in help seeking behaviours

Both men and women studied tended to seek diagnosis later on in the course of their illness except those whose diagnosis was related to health policy e.g. antenatal screening. Both men and women were eager to manage information about their symptoms and to maintain normality. This implies that they delayed help-seeking and consequently, late diagnosis. Both men and women showed gaps in knowledge and information about HIV and AIDS and this was reflected in their help-seeking patterns. Information and knowledge about HIV and AIDS are essential in motivating people to seek help. Such gaps in information and knowledge explain the different perceptions of HIV and AIDS held by participants which affected their help-seeking behaviour. Both men and women studied had issues with physical and psychological access as explained earlier on this chapter. All perceived the segregation and isolation of HIV facilities differently from what such segregation was intended for and this had a potential negative impact on help-seeking. Both men and women were cautious about both intentional and unintentional disclosure and therefore struggled to manage information about their diagnosis in an attempt to maintain normality.

7.12.2 Differences in help-seeking behaviours

Despite the similarities in help seeking between men and women studied, there were some differences. More men than women studied practised voluntary testing for HIV. Voluntary testing was observed in those who were involved in unsafe sexual practices. Men were more likely to be involved in unsafe sexual practices than women and were therefore more likely to test for HIV and AIDS voluntarily. Additionally, men in the study were more open about the modes of transmission of HIV and AIDS than women and were more likely to recognise the biologic basis of HIV and AIDS unlike women who recognised the causes of HIV and AIDS in terms of lay beliefs or conspiracy theories.

The potential differences by gender in their health behaviours, confirms the low status attributed to women and the issue of “silence in pain” (hook 1981, Goheen 1996) within the sub-culture of the black African and African-Caribbean groups. Women in the study were unable to speak and act in making decisions about managing and ending relationships with their male partners even though they were aware of their multiple sexual relationships. This explains the enshrined culture of informal practice of “polygamy” in the UK (Rivett and Street 1993, Menski 2001), though legislation does not permit such relationship. Universal conventions like the right of people to health and fighting violence against women is not observed.

Tolerating multiple partnerships confirms the finding of Awah et al (2009) that people move with their cultures so black Africans and African-Caribbean people also move with their cultures. This inhibits the capacity of women to live healthy lives and to have the right to freedoms enshrined in the Universal Declaration of Human Rights. This, in itself, exhibits the

‘Africanness’ and its associated concepts. Identifying with HIV and AIDS further accentuates the silence. In this situation, there is the understanding that it may be normal for black African women to believe that sustaining a sexual relationship with a black African man should expect subsequent infection with HIV, yet no freedom to complain. One of the Millennium development goals (MDGs) was to create gender equality by 2015 and this work has illustrated that with less than two and half years to be in 2015, this goal is still far from being achieved amongst black Africans and African-Caribbean people living in the UK. This study has clearly illustrated that women in black African and African-Caribbean communities are neither able to have their voices heard nor to make decisions concerning their own bodies especially decisions around multiple partner relationships which place them at risk.

7.13 Implications of Findings for professional practice

The model of help-seeking by these groups of people clearly shows inter-linkages in the pathways to seek help and these have implications for professional practice. From the model, biomedicine is accessed as a last resort when symptoms fail to respond to both self-care and CAM. Biomedicine can be described as mechanistic because of its failure to engage with the psychosocial and spiritual aspect of the individual. It assumes that disease is an organic condition and non-organic factors associated with the human mind are of no importance in the search of biological causes of pathological symptoms. Biomedicine lays emphases on expertise not tradition and folk beliefs and maintains that, critical inspection and control through scientific and technical regulation are important.

Applying this model to dealing with illness in western cultures is understood but applying it in the west to address illness in people from non-western cultures is likely to compel them to

seek other ways of getting healing other than biomedicine because they understand healing holistically. Biomedicine is accessed at a later stage when it legitimises and names the illness and initiates the process of recovery or draws attention to the possibility of the end which is death depending on the stage at which the legitimisation is done. From the literature these individuals live a communal lifestyle and the bio, psychosocial and spiritual dimensions are very important to them. Moreover, illness in the western culture is understood from the biomedical perspective. On the contrary, the groups studied understand illness from a bio, psychosocial and spiritual perspective. Given that HIV and AIDS are stigmatising, these dimensions are exceptionally important for healing and coping among these groups of people which biomedicine is unlikely to offer. Health professionals have to recognise this and may need to use a holistic approach in dealing with people from non-western cultures.

Self-care and the use of CAMS were used by most of the participants. Unlike biomedicine, there is no process of legitimisation of symptoms with these approaches to help-seeking but the individual is treated holistically. The sick individual is known as a person and not by the disease. Health professionals may need to adopt this approach as this will likely attract people from non-western cultures to test voluntarily for HIV.

As discussed earlier on in the chapter, Britain is noted for its assimilationist principle. This implies that these groups of people have to fully integrate into the British way of life by adopting the British culture and speaking English as their main language. While this is likely to be problematic, health professionals seem to overlook the importance of providing information (verbally and by leaflets) in languages that are best understood by these people (service users) some of who have French, Arabic and Swahili as their first languages. In other

to improve their help-seeking behaviours, efforts have to be made by the health service to provide information to them in an understandable form.

From the findings, cultural incompetence was a problem among the health professionals. Papadopoulos et al (2004) have pointed out that it is important for health professionals to gain cultural understanding of the different ethnic groups that they deal with as such understanding will also help them to understand their health beliefs and consequently their health behaviour. Therefore, health professionals should be culturally sensitive to people under their care and see them as true partners.

One of the problems that these groups of people faced is confidentiality. The way sexual health services in the setting studied are located and organised is likely to affect confidentiality. It is therefore important for health professionals to look for ways of integrating sexual health services with other services. This will potentially normalise the testing process and may attract more people to test voluntarily.

7.14 Strengths, Limitations and challenges

This study has several strengths. First and foremost is the perspective it provides about the way cultural factors influence decisions about seeking help with stigmatising illness like HIV and AIDS and also how cultural misunderstanding can make the healthcare system to misinterpret the needs of their patients. Participants from both backgrounds were able to give accounts of their experiences in seeking a diagnosis while trying to maintain normality in public and these highlighted those aspects that help to determine pathways to help-seeking with stigmatising illness. Using a reflexive approach enabled me to highlight the possible

sources of bias especially as the research involved people some of whom shared a common ethnicity with the researcher.

This study uncovered the notion of ‘Africanness’ and highlights the impact of ‘Africanness’ on seeking help for HIV and AIDS diagnosis and care. Adopting the notion of ‘Africanness’ was produced from my research data and looked at the risk factors for contracting or transmitting HIV that formed a category that was a marker of African identity. The study also produced a model of help-seeking adopted by the groups of people studied. These add to the knowledge base in medical anthropology and sociology of health and illness literatures.

It is already well-known that black Africans and African-Caribbean people delay help-seeking to diagnose HIV despite the availability of free and confidential HIV screening services and the availability of HAARTS. Consequently, they are diagnosed at an advanced stage of their illness. This is the case in the UK and it has been shown that seeking biomedical health care was not the priority of the groups studied, for example, Ibrahim et al (2009) has pointed out that black Africans in particular, in the UK prioritise economic issues than health issues. This study by exploring two different groups, and men and women has examined how they deal with health issues using three concepts (broken narratives/silences, biographical disruption and biographical abrupton) as a lens to examine this.

The people studied start their help-seeking process by self-medicating and/or seeking alternatives to biomedical care to resolve their symptoms while maintaining a ‘false’ sense of normality through silences. It is when these symptoms fail to resolve at which stage they have no further options that they seek biomedical healthcare. This study has therefore provided a reason for delays in seeking timely biomedical help. This will enable the NHS to review its

strategy in reaching out to black minority groups not only black Africans and African-Caribbean but also Asians. Hopefully, this will provide a starting point for policy makers to review their health promotion and disease prevention strategies.

The study was limited in that firstly it focused only on those patients who had already been diagnosed with HIV and thus it does not capture the views of those who may or may not have symptoms and who have not yet been diagnosed. The study also focused on a cultural approach. It was a purely patient-centred study without recourse to health care providers and other lay care providers. Such a group could provide a wider understanding of the decision making process and justification of choices of pathways as they are lived by those still to reach the biomedical scenery.

Being black African and female and in a position as the researcher, researching black Africans and African-Caribbean people with an African ancestry in the clinical setting created a sense of ‘guarding’ especially with black Africans. It is likely that the cultural background of the researcher as well as the professional status may have influenced the interview relationship and consequently the responses obtained. Although the participants made no explicit reference to this factor before, during or after the interview, some behaviour during recruitment and interviewing provided evidence that the willingness to share their stories was both influenced and inhibited.

The study was limited only to those who could speak and understand English but many African-Caribbean and African countries speak French, Arabic and Swahili. Many potential participants could not speak English fluently and French speaking participants could have been included in the study as the researcher spoke and understood both French and English and many patients were French speaking Africans. Being a sensitive subject involving

personal stories and painful memories implied that the services of an interpreter were not appropriate. Using a translator especially for Swahili and Arabic speaking patients might have brought about the issue of reliability in the translations and a problem of interpretation without distorting their actual meaning.

7.15 Directions for future research

This study sets the pace for understanding African related cultures of illness. Similarly, the growing Indian and Asian sub-cultures found in the UK need similar findings to strengthen interventions for chronic diseases prevention and treatment.

The model of help-seeking for these two groups of people developed from the study provides insights to the complex and lengthy pathways followed by these groups with illness. These pathways are influenced to a great extent by cultural factors. To cause behaviour changes among these groups in relation to help-seeking for diagnosing HIV and AIDS, targeting those who are uninfected or who do not know their status may provide valuable insights into factors that could attract these group to the biomedical scenery earlier on during their illness career. It may therefore be worthwhile to explore the perceptions of non-HIV infected black Africans and African-Caribbean people of seeking help for diagnosis of HIV and AIDS. It may also be important to explore health professionals' understanding of lay beliefs.

Non-biomedical regimens continue to be used by many people especially black Africans to control symptoms of HIV and AIDS both in Africa and the UK evident from this study. Although, there has been no evidence to date of a complete cure of HIV and AIDS using non-biomedical regimens, black Africans in particular are convinced of their effectiveness. These

regimens may be effective against symptoms, as already discussed elsewhere in the chapter; an African approach to dealing with the ‘African thing’ is cultural and symptomatic. It might therefore be worthwhile exploring the experiences of black Africans living with HIV and AIDS on non-biomedical regimens. It may be interesting to know how cultural beliefs affect adherence to prescribed treatments and outcomes of care in a multi-ethnic culture. It may also be interesting to see what result would be yielded if a similar study was conducted by someone without any ethnic link with the population being studied.

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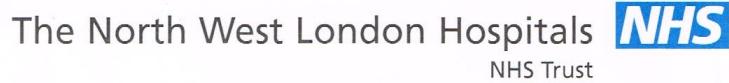
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Appendices

Appendix 1: Research Participants consent Form



Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

Participant's I.D No -

Tel: 020 8864 3232

CONSENT FORM

TITLE OF PROJECT

Help Seeking Behaviour of Black Africans and Black Caribbeans to diagnose
HIV/AIDS.

Project No: - 13183/18462/1/448

Name of Researcher: Concilia Ajuo

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.....
2. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving any reason and this will not affect the services I am offered at this Clinic.....
3. I understand that only the researcher and her supervisors will have access to the transcripts which will be treated as confidential.....
4. I agree to take part in the above study.....

Name of Participant

Date

Signature

Researcher

Date

Signature

Version: 1.0

Trust Headquarters: Northwick Park Hospital, Watford Road, Harrow, Middlesex HA1 3UJ Tel: 020 8864 3232
www.nwh.nhs.uk

We are Smoke Free. Smoking is not permitted in our hospital, grounds or vehicles.
For free advice and support on giving up smoking, call 0800 169 0169

Appendix 2: Research Participants Information sheet

PATIENT INFORMATION SHEET

Help seeking behaviours of black Africans and black Caribbean to diagnose HIV/AIDS

This is an invitation for you to take part in a research study. Before deciding to be part of the study, it is necessary that you are aware of reasons for doing the research and a brief overview of what it involves.

Please read through the following information carefully. It is in two parts:

Part 1 tells you the purpose of the study and what will happen if you take part.

Part 2 consists of more detailed information about the conduct of the study. Please do not hesitate to contact me for more detailed information or for any clarification you may require.

Thank you.

Part 1

What is the purpose of the study?

The purpose of this study is to examine the help seeking behaviours of black Africans and black Caribbeans in diagnosing HIV/AIDS

Why have I been chosen?

All patients attending the genito – urinary – medicine clinic aged between 18years and fifty years of age and of black African or black Caribbean ethnicity and who can read and write in English are being invited to participate in the study.

Do I have to take part?

Participation is voluntary and you are free to withdraw at any stage of the study without any justification. Note that your decision to withdraw will not affect the quality of service or care you receive.

What will happen to me if I take part?

You will be interviewed about your behaviour in coming to seek diagnosis for your condition including any help you have received prior to attending this clinic. It should take about an hour. We are asking about 30 people that attend this clinic to participate. Names shall not be included which means that anyone taking part cannot be identified.

At the end of this leaflet is a form inquiring whether you would like to be invited to take part in the interview. If you agree to take part you will be one of 30 people who attend this clinic who will be interviewed.

What do I have to do?

Simply sign the consent form and complete the information request form at the end of this leaflet and return them to me in the prepaid envelop provided. If you would require more information about the study, this will be sent to you as soon as possible.

What are the possible disadvantages and the risks of taking part?

There are no disadvantages and no risks and you can withdraw from the study at any time.

What are the possible benefits of taking part?

There is unlikely to be any personal benefits from taking part. However your participation might help in the improvement of access to health services by black ethnic groups.

What happens when the research study finishes?

If you wish, we will send to you a summary of the findings when the research project finishes.

What if there is a problem?

It is unlikely that something may go wrong during the interview. However if this does happen, it will be dealt with immediately. Detailed information is given in part 2.

For more information on this study, please contact:

Concilia Ajuo

Northwick Park Hospital NHS Trust

Telephone: *inserted*

Email: *inserted*

PART 2

What if there is a problem?

As this is an interview, it is unlikely that anything could go wrong. However if you have any concerns about any aspect of this study, speak with the researcher who will answer your questions. **Please contact Researcher on xxxxxxxx.**

If you are harmed by taking part in this research projects there are no special arrangements but if you are harmed due to someone's negligence, you may have grounds or legal action for compensation against the Northwest London Hospitals NHS Trust but you may have to pay for it. The normal NHS complaint mechanism is available to you if you wish to complain about any aspect of the way you are approached or treated during the course of the study.

Formal complaints should be addressed to:

NHS Patient Advisory Liaison Services (PALS).

Northwick Park Hospital

Watford Road

Harrow

Harrow Middlesex

HA1 3uj

Tel: 02088695118

Should you require independent advice about making a complaint or seeking compensation, you may wish to contact the Independent Complaint Advisory Services (ICAS):

The Independent Complaint Advisory Service (ICAS)

Northwick Park Hospital

Watford Road

Harrow
HA1 3UJ
Tel: 02088695118

Will my taking part in this Study be kept confidential?

All information collected in this project will only be accessed by the relevant research staff and this information will be kept on a secure personal computer only accessible to me with a password protection. All information you will provide will be treated confidentially and you will not be identified in any report or publication arising from this project.

What will happen to the results of this study?

At the end of the study the researcher will send a report of the findings to Northwick Park Hospital and to any organisation that has been involved in the study. If you wish a summary of the findings will also be sent to you. You will be informed if the results are to be published.

Who is organising and funding research?

Self funded.

Who has reviewed this study?

The study has been given a favourable ethical opinion for conduct by the /Brent Medical Ethics Committee.

Thanks for reading this information sheet. You may keep the sheet.

Appendix 3: Participant recruitment response form

Interview Response Form

Yes I am interested in receiving information about the interview and I am interested in taking part.

Name (please print)

.....
.....

Address (please print)

.....
.....
.....
.....
.....
.....

Telephone number-----

Sign.....

Appendix 4: Letters of information

Appendix 4a

Northwick Park Hospital
Watford Road Harrow

Concilia Ajuo
Operating Theatres

HA1 3UJ

17th November 2008

Dr. Gary Brook
Consultant Physician
Patrick Clement's Clinic
Central Middlesex Hospital
Acton Lane, Park Royal,
NW10 7NS

Dear Dr Brook,

Subject: Letter of information and Request for Access.

I am undertaking a professional PhD in Health Research at the University of Hertfordshire. As part of the course requirements I will be undertaking a research study on the topic: ***Help seeking behaviour of black Africans and Black Caribbeans to diagnose HIV/AIDS.*** This study is supervised by Professor Hilary Thomas, a sociologist and Dr. Julia Williams both of the University of Hertfordshire.

I kindly request for access to the GUM Clinic to enable me work with the HIV/AIDS patients consulting at your clinic. I will be very grateful if you grant me access.

The study will involve confidential interviews with HIV/AIDS patients of black African and black Caribbean backgrounds attending the GUM Clinic. These interviews will take place at a place and time convenient for the patients.

The Brent Local Research Ethics Committee requires that I inform you that this study will be taking place. I enclose a brief project summary and a copy of the participant information sheet.

Thank you in advance for your support.

Yours Sincerely,

Concilia Ajuo

Appendix 4b

13th August 2009

Dr. A. Shaw
Consultant Physician
GUM Clinic
Northwick Park Hospital
Watford Road Harrow
HA1 3UJ

Dear Dr Shaw,

Subject: Letter of information and Request for Access.

I am undertaking a professional PhD in Health Research at the University of Hertfordshire. As part of the course requirements I am undertaking a research study on the topic: ***Help seeking behaviour of black Africans and Black Caribbeans to diagnose HIV/AIDS***. This study is supervised by Professor Hilary Thomas, a sociologist and Dr. Julia Williams both of the University of Hertfordshire and Dr. Gary Brook of Patrick Clements Clinic Central Middlesex Hospital.

I have been recruiting participants at the Patrick Clements Clinic but this has rather been slow as the inclusion/exclusion criteria are very limiting. I would like to recruit from the Northwick Park clinic as well and have been asked by R&D to write to you. I kindly request for access to the GUM Clinic to enable me work with the HIV/AIDS patients consulting at your clinic. I will be very grateful if you grant me access.

The study will involve confidential interviews with HIV/AIDS patients of black African and black Caribbean backgrounds attending the GUM Clinic. These interviews will take place at the clinic at a time convenient for the patients.

The study has been approved by the Brent Local Research Ethics Committee. I enclose a brief project summary and a copy of the participant information sheet.

Thank you in advance for your support.

Yours Sincerely,

Concilia Ajuo
Theatres
Northwick Park Hospital.
Tel – 02088693982/3
Email – Concilia.Ajuo@nwlh.nhs.uk, cajuo@btinternet.com

Appendix 4c

Dr Alan Warnes
R&D Director
North West London Hospital NHS Trust
Research and Development Office
Room 008, Level 5BB
Watford Road
Harrow
HA1 3UJ

20 – 11 -2008

Dear Dr Warnes

Re: help seeking behaviour of black Africans and black Caribbeans to diagnose HIV/AIDS

Project No. (R1): I

Chief Investigator – Concilia Ajuo

Supervisors: Professor Hilary Thomas and Dr. Julia Williams

This letter is confirm that the above project complies with the University of Hertfordshire's research governance criteria. On this basis the University is willing to act as sponsor.

The project is not a clinical trial according to the criteria laid out by UM Association Ltd insurers and therefore indemnity can be given. A copy of the letter of indemnity is attached. Any changes to the duration of the project, investigators, or deviations from the protocol may negate this cover and sponsorship arrangements. Therefore you must inform the University of Hertfordshire research office and awarding ethics committee of any such changes.

Yours Sincerely,

Prof John Senior
(Pro – Vice Chancellor – Research)
University of Hertfordshire,
College Lane,
Hatfield
Herts, AL10 9AB
Tel: 01707 284 301
Fax: 01707 284 782

Appendix 5: Interview Guide

Northwick Park Hospital NHS Trust

Telephone: 0789 035 6403

Email: cajuo@btinternet.com

Help-Seeking Behaviours of black Africans and black Caribbeans to diagnose HIV/AIDS.

INTERVIEW GUIDE

Attitudes towards help seeking

- Greetings – How are you/how do you feel today
- Reasons for seeking medical attention?
- Tell me how you started receiving treatment in this unit.
- Options available for seeking help
- Actions taken before seeking medical attention
- Did you speak to anyone when you started suspecting that you were unwell? (If yes, why? If no, why?)
- Feelings about the medical treatment of your health condition?
- Feelings about your illness?

Perceptions of access to health services

- Knowledge of other HIV facilities
- Reasons for choice of clinic.
- Feelings about treatment and services received in the clinic
- Experiences of accessing the services offered in the clinic
- What do you think will make GUM clinic services better for you
- What do you think can be done to encourage black people to attend the GUM clinic when they are unwell?

Other forms of help

- Knowledge of other forms of therapy available for managing your condition. (Probe for alternative medicines, food supplements, religion`).
- Other form of help that you sought before coming to the GUM clinic.
- Information you receive (from here or elsewhere) about your condition.
- Adequacy of information received

Knowledge of Service

- Where do people generally go when they have problems with HIV? What about you?
- Probe for GUM clinics (if it is not mentioned).
- How did you know about the health unit where you seek help?

Generalities

- Common health problems that worry people in your community If HIV is not mentioned, (prompt).
- Why do you think people have these problems? If HIV is not mentioned, (prompt)
- Please, tell me what people think about HIV? (Prompt for the causes and beliefs).

Socio - demographic data

1. Age
2. Sex
3. Ethnicity
4. Marital status

Appendix 6: Ethics Approval Letter



Brent Medical Ethics Committee

Room 019, Level 7 Maternity Block
Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

Telephone: 020 8869 3805
Facsimile: 020 8869 5222

04 February 2009

Mrs. Concilia N. Ajuo
Theatre Sister
THE NORTHWEST LONDON HOSPITALS NHS TRUST
NORTHWICK PARK HOSPITAL
WATFORD ROAD HARROW
MIDDLESEX
HA1 3UJ

Dear Mrs. Ajuo

Full title of study: HELP - SEEKING BEHAVIOUR OF BLACK AFRICANS AND
BLACK CARIBBEANS TO DIAGNOSE HIV/AIDS.
REC reference number: 09/H0717/7

The Research Ethics Committee reviewed the above application at the meeting held on 26 January 2009. Thank you for attending to discuss the study.

Ethical opinion

In discussion, the Committee noted the following ethical issues.

1. The committee commented that the application was thorough and very well written.
2. The committee was concerned that the researcher may be putting herself at risk by offering to meet potential participants at a venue chosen by them and suggested that the venue should be within the Hospital.
3. The committee requested that on the letter of invitation please add "potential" before "participant".
4. The committee asked how the sample size had been chosen.
5. The committee requested clarification of what procedures were being adopted to ensure confidentiality - would they comply with GUM clinic procedures as they usually have lists of contacts who have agreed to mail being sent to a confirmed address.
6. The committee asked whether 2 months would be adequate to complete the study.

Mrs. Concilia Ajuo was invited to join the meeting and the Chair welcomed her and asked for a brief explanation of the proposed study and the main ethical issues in her opinion.

Mrs. Ajuo explained the origin of the idea for this study and the main ethical issues in her opinion to the committee.

- A. The Chair asked Mrs. Ajuo where the study will take place and Mrs. Ajuo confirmed that it would take place at Central Middlesex Hospital.
- B. The Chair asked whether the study would be completed in the 2 month window specified in the application form. Mrs. Ajuo informed the committee that she will be taking annual leave for this period to ensure completion. The Chair was concerned that Mrs Ajuo was taking annual leave to complete her research and suggested that R & D review this point under Health & Safety contravention.
- C. The Chair expressed concern for the researcher's own safety in relation to the venue

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chosen to meet them. Mrs. Ajuo replied that she had stated a place that would be convenient for the participant as she was asking them to participate in the study however she could ensure that it was in the hospital. The Chair requested that Mrs. Ajuo confirm a suitable venue in the hospital once it has been arranged. Mrs. Ajuo replied that she would find a suitable counselling room and ensure that she would be able to get help if she felt threatened in any way.

- D. The Chair asked Mrs. Ajuo to clarify how she was going to approach the potential participants. Mrs. Ajuo confirmed that she would give potential participants the information sheet in the clinic. The Chair asked for clarification of the postal contact that Mrs. Ajuo will have with potential participants as the committee was concerned about breaches in confidentiality through circumstances beyond her control. Mr Ajuo confirmed that she would not be sending anything through the post to the participants as she will be approaching them in clinic. She would at that point give the PIS and self addressed stamped envelope which could be used by the potential participant to send their consent form back to Mrs. Ajuo. The committee noted this point.

Mrs. Ajuo agreed to initiate the conditions and left the meeting at 6.55 pm.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

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.

Management permission at NHS sites ("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 is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

Other conditions specified by the REC

The Chair thanked Mrs. Ajuo for submitting a well thought thorough application and informed her that the study had obtained a favourable opinion with the additional conditions as follows:

- A. To confirm a suitable venue at the hospital for the participant interviews.
- B. To add on the letter of invitation please add "potential" before "participant".
- C. To add on the PIS in the first line of the introduction "whether" after "Before deciding.."
- D. To confirm the study end date in writing as December 2011.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		05 January 2009
Protocol	1	29 November 2008
Investigator CV		20 November 2008
Application	2	16 December 2008

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CV for Professor Hilary Thomas		15 December 2008
Participant Information Sheet	2	14 May 2008
GP/Consultant Information Sheets	Dr Gary Brook	17 November 2008
Letter of invitation to participant	1	12 June 2008
Participant Consent Form	1	14 May 2008
University Degree Board-Approval letter		16 December 2008
Sponsor Letter to Dr Warnes		16 December 2008
University of Hertfordshire Professional Indemnity		01 August 2008
Interview Guide	2	18 June 2008
Letter to Participants-consent		
GP/Consultant Information Sheets	Mr Jonathan Davies	17 November 2008
Peer Review	Justin Gore	

Membership of the Committee

The members of the Ethics 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.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0717/7	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely

PP. 
Dr Bernie Colaço
Chair

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Email: Mona.Shah@nwlh.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers" [SL-AR2 for other studies]*

Copy to: Professor John Senior, University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB

Dr Alan Warnes, R & D Manager, NWLH NHS Trust.

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Brent Medical Ethics Committee
Attendance at Committee meeting on 26 January 2009

Committee Members:

Name	Profession	Present	Notes
Dr Kofi A Anie	Clinical Psychologist	Yes	
Mrs Sunder Chita	Manager	Yes	
Dr Bernie Colaco	Consultant Rheumatologist	Yes	
Dr Neeta Ghosh-Chowdhury	General Practitioner	Yes	
Dr Sanober Haque	Doctor of Medicine	Yes	
Ms Homa Syeda Hasan	Bioethics Adviser	No	
Mr Maurice Hoffman	Teacher	Yes	
Mr Paul James	Chief Audiologist	No	
Dr Wing May Kong	Consultant Physician and Honorary Senior Lecturer	Yes	
Mrs Shaheda Lakha	Oncology and Clinical Trials Pharmacist	No	
Mr Adeyemi Olagbegi	Clinical Pharmacology Study Data Manager	Yes	
Mr Howard Woolfson	Senior Exam Invigilator	Yes	
Miss Ourania Xeniou	Clinical Research Associate	Yes	
Miss Zainab Yate	Research & Performance Officer	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mr Suresh Akula	Retired Accountant – potential member
Mr Sinan Alsaffar	Pharmacist – potential member
Mrs Alka Bhayani	Ethics Administrator
Mrs Mona Shah	Committee Coordinator

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NHS
National Research Ethics Service

Brent Medical Ethics Committee
Room 019, Level 7 Maternity Block
Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

Telephone: 020 8869 3805
Facsimile: 020 8869 5222

04 February 2009

Mrs. Concilia N. Ajuo
Theatre Sister.
THE NORTHWEST LONDON HOSPITALS NHS TRUST
NORTHWICK PARK HOSPITAL
WATFORD ROAD HARROW
MIDDLESEX
HA1 3UJ

Dear Mrs. Ajuo

Full title of study: HELP - SEEKING BEHAVIOUR OF BLACK AFRICANS AND
BLACK CARIBBEANS TO DIAGNOSE HIV/AIDS.
REC reference number: 09/H0717/7
Protocol number: 1

Thank you for your letter of 02 February 2009. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 26 January 2009. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		02 February 2009
Letter of invitation to participant	2.0	02 February 2009
Participant Information Sheet	2.0	02 February 2009

09/H0717/7 **Please quote this number on all correspondence**

Yours sincerely

Mrs. Mona Shah
Committee Co-ordinator

E-mail: Mona.Shah@nwlh.nhs.uk

Copy to:

Professor John Senior, University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB

Dr Alan Warnes, R & D Manager, NWLH NHS Trust.

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Appendix 7: Research Governance Approval



R&D Office
Rooms 7N 014, Level 7, Maternity Block
Northwick Park Hospital
Watford Road, Harrow HA1 3UJ
Tel: 020 8869 2011
Fax: 020 8869 5081
E-mail: alan.warnes@nwh.nhs.uk
Website: www.nwh.nhs.uk/research

NHS Management Approval Letter for Research

To: Concilia Ajou (Supervised by Dr Gary Brook)

From: Dr Alan Warnes (R&D Manager)

Date: 03rd April 2009

Project Title: Help-seeking behaviour of black ethnic groups to diagnose HIV/AIDS
(RD9/019)

I understand that you have received a favourable ethics opinion for the above project, with the condition that you do not undertake research in an NHS organisation until relevant NHS Management Approval has been received. I am therefore writing on behalf of the North West London Hospitals Trust to inform you that the project has been approved by the Trust and may now proceed.

To maintain this approval, the following conditions must be met:

1. All staff involved in the running of this study must adhere to Trust and Research Governance Framework requirements (see www.nwh.nhs.uk/research).
2. As Chief/Principal Investigator you are required to formally advise the R&D Office of **ANY** changes to the project including:
 - Any changes to the status of the project, e.g. abandoned, completed etc
 - Any changes to the protocol – however minor.
 - Any changes to the funding arrangements.
3. The Chief/Principal Investigator is also required to:
 - Notify the R&D, in a timely fashion, any Serious Adverse Events relating to the Research and the appropriate urgent safety measures taken in line with ICH GCP requirements.
 - Ensure that the R&D Office has copies of all annual and final progress reports.
 - Ensure all researchers involved in the project hold the necessary expertise required and have Honorary Contracts should they need to.
 - Ensure adequate and accurate reporting and monitoring of said project.
 - Co-operate with all internal Trust monitoring and auditing procedures.

Appendix 8a: Block and file analysis – Group 1 – AW

BLOCK AND FILE APPROACH (GRBICH 2007)

GROUP 1 - AFRICAN WOMEN

Participant	Reasons for attending clinic	Sources of information	Knowledge about HIV/associated D'ses	Disclosure/broken narratives	Therapy sort	Africanness	Perception of HIV/victims	Quality of service/Access
E176AW(38)	Getting tired and weak, kept going to the GP, genital warts, persistent boils. Had attended GP several times but GP refused to offer HIV test that there was no need for it. Kept saying there was nothing wrong, Boils not going away, Ear infection, Told a friend, and brother; Get it checked out, Came to clinic, Self referral, Showed my brother, Asked to test for HIV, HIV not for me, Do it for records I wanted somewhere that's a bit away from home.	Far away from home so I don't meet anyone I know recommended by friend yes I was given leaflets which I destroyed, reason being I've got friends coming in and out. I don't want anybody picking it up by mistake or picking any information that will say oh, that will indicate what I'm going through, you know that's my reason. But I do read it, I read it and destroy it	Hepatitis B Media not for black people, My reaction to TV advert is to switch channel off. Didn't want to hear about HIV; not for me; I'm not wayward I don't think anything of it. I think the way I'm handling it, the biblical way is what is really helping me bcos there's nothing anybody can tell you that will change what you believe., so nomatter what they say, to me, I know they haven't got the final say, or the final authority so, from their own perspective it wouldn't make any difference because you don't have it , bcos somebody will come and say don't worry. Its only he that wears the shoes knows where it pinches him; it is you who is suffering it knows how you feel.	Will not tell anyone especially my mum, not even my friends that I have HIV. Attend clinic far from home, have friends at NPH so can't go there, Can't explain why I attend hosp every 3months, am Christian, can't lie. I did tell my church I've got hepatitis, which I do have. It's not like I don't have it but I haven't given them a true picture of all I've got.	Conventional treatment Spirituality Spiritual therapy, incurable diseases , Trusted god , Not medication sustaining me. You want to tell them of the worldly way of going about it. I have heard of testimonies, I don't know whether you're a Christian but I won't assume but I hear testimonies of people who have incurable conditions and the doctors could not explain how it happened. The person himself cannot explain but only knew that, I was prayed for, I trusted god and something shifted for my sake	They will ostracise me AIDS is judgement, equate to leprosy, Ostracised, segregated, Separation, and it hurts. After a while they begin to ostracise you. When you use a cup, they disinfect it quickly even when you are not watching and when you have close friends, when you want to go to them, normally they used to come to your house and eat and feel free and spend the weekend but as soon as you open your mouth, nobody comes to you	Promiscuous, prostitutes, wayward lifestyle, leprous. Fear , judgement, positive, I just felt you know, getting involved with anybody now is like a death warrant. I've been praying for getting a husband, get married soon and have children and stay with somebody. Except the person is like me, of course, which man, will, and how will I start explaining to this man that I have something?	I wouldn't really see what the treatment is really doing for me; because as it is right now, I wasn't really ill. If I had been ill, probably I would have noticed a great improvement but because I wasn't really ill when it was discovered and the only thing I had was that rash or the boil, Not at ease with the segregation..Anyone in the lift seeing you press second floor start to look at you. They know straight away that you are coming here I think they have been excellent. The first, first, first few months, you know was very difficult for me because I thought everybody was watching me and will be shaking their heads and saying: "oh my god! You mean this girl has it?
A086AW (49yrs old widow) CD4 - 60	Fever, gastric problems, wt loss, weak, pale, armpit swelling, diarrh, pubic boils, loss of appetite,	That counsellor was very nice. He said I'm positive.' And my docta was positive too.	But I think in Africa, back in my mother's country which is Uganda, they have tried their best. Everywhere	Keep problem with me, social worker lied to my daughter that I had kidney probs,	Conventional therapy at late stage. I am an ordinary Christian, simple catholic.	My hussy was moving with other women (polygamy), Africa will throw me out, they'll hate me, they'll	Womaniser, prostitute. it goes with shame, some of them,most of them, but I think back in Africa, yes, it's like you	Medications ok, doctors and nurses very caring, show you love, make you feel like a normal person, change your

	<p>hair loss like Somali, rashes, sunken eyes, oral thrush, vaginal thrush.</p> <p>Had done hiv test b4 in Africa and was -ve, had requested for it to be tested here but GP said I'm ok and there was no need.</p> <p>Husband died 10yrsago, unwell in 2005, fever, negative, asked for HIV test, told i'm alright, nothing wrong on xray, oral thrush, my husband died of AIDS, can't be alright, hiv screening not well developed in Uganda</p>	<p>I think all the information I need. I don't know what is left out. I know how to take my medications, I know what to do I've seen the health adviser and she has advised me on many things.</p>	<p>they are on TV, everywhere, no shame; come to the clinic, come to the clinic, we will not say anything. Come to the clinic.</p>	<p>my husband died of AIDS but we told lies to my daughters, if I tell my them that I have hiv, they will throw me out, they'll hate me, they will segregate me. It goes with shame</p>		<p>Because they were here when he fell ill, So they just came to see him on his death bed, he had thrombosis in the beginning and we just created a story and when they ask this, what their father died of and, in Africa, everything is possible. They ask for a death certificate and it was issued with another type of illness. The wives have passed. It was like a polygamous marriage. I was married in church with him but he kept on moving with other women like, you know the African men. African men, you can't stop them; the society here, the African society here are also there to talk about people, the African way so I don't worry to mingle with them so much so that's all. I keep to myself.</p>	<p>haven't...done it... but everybody does that everyday but when you contract HIV, everyone says, ah, he is a womaniser, you see, this and that, you know, no respect.</p>	<p>medication at the slightest problem, don't look down on us, they care, they do referrals e.g. to social services, have all info need, know how to take my medication, know what to do.</p>
P086AW (34yrs) CD4 - 74	<p>Prolonged & recurrent pneumonia, falling sick, diarrrh, vomiting, growing lean, not eating well</p>	<p>Dr M... always gives me advice never to stop taking my treatment and the kind of treatment</p>	<p>Pneumonia I just told myself, well they've been showing people on television, they live with HIV, with HIV/AIDS and they are living a normal life; why can't I just cope with it and keep on taking my medications whereby I'll be able to live for a longer life.</p>	<p>Can't tell my family, can't tell friends because once they know, they keep their distance, no one will use your cutlery</p>	<p>Conventional, spiritual aspect, sanctity, massage and 'shahitru' a type of massage Some people can do; people who may feel shy to come to the clinic to talk to the doctors and nurses about their problem. Some may seek not to come at all, some</p>	<p>I think this disease is an African illness, I see lots of African people here. Back home I know people who live with it. Even if they touch a spoon or a glass they use to drink, nobody in their family will like to use it.</p>	<p>Abnormal people, living with stigma. I do classify myself as not being normal because I live with a stigma whereby, when people get to know, they may try to redraw from you as a friend or something of that sort;</p>	<p>They welcome you, talk nicely, make you feel normal, make you forget about illness. The environment makes me feel welcome and I feel like a normal being living without any kind of sickness or disease..</p>

					<p>may seek to go to church and rather be praying. They may go to the church also and they may talk to the pastors about their problems but I would prefer for them to come to the clinic too, to have their medications and be going to the church at the same time.</p>		
C149AW 11/2yrs into dx,	Dating a man with piercings all over his body, piercings on penis, suspected he was bisexual, tattoos, had sex while bleeding, suspected he could be infected.	Rang 118118 b/c did not know of any sexual health clinic. I did receive some leaflets & a magazine, I found them very useful bcos you want to read as much as possible. From the internet, because sometimes, there are some parts that you are asked to put in your meals so I started adding that to my meals as well; things you will not normally do before, just basically anything that can, you know. I read up on research that has been carried out in China or India or whatever basically. You've got a lot on the internet.	I used to dread the pictures of those Africans that they show on TV with a lot of things on their faces. I will not like to look like that. I always like to be pleasant to be looked at.	I will only tell people that genuinely love, me, told the 3 men that wanted a r/nship with me, told my former BF, told my GF and asked her to tell her husband. Wldn't tell mum and daughter, both are vulnerable. prefer telling white friends b/C they are non judg'tal	<p>Handed it to god, believe in proper nutrition, not yet on conventional therapy. People normally go to church, then to Africa b/C if WHO stats on HIV in Africa are right then herbal remedies in Africa are very effective. Have seen Africans who have been sick and gone to Africa and have returned healed</p> <p>I think I would research what Africans are never, because despite what WHO are saying, millions of Africans are honestly, and obviously I think the treatment would be, I think there would be some herbal remedies because it is our bodies. We've got AIDS in Africa; there would be herbs that probably do not have side</p>	<p>Africans are less understanding and are more judgemental. Africans see HIV as the end of life, when you tell them you are +ve their typical reaction is crying. I will not go intentional infecting other people like Africans do and remain in denial. A lot of Africans, our men, the attitude of our men may be to blame bcos they do not like to use protection. For me, what getting this has done is, you see whereas in the past, somebody could put pressure on you and then you say ok, now 'over my dead body' I told her and she couldn't say anything and she said and for how long have you known and you haven't told me and I said your reaction is exactly why I haven't told you ok. This is just a typical African reaction</p>	<p>Gloving, 'danger of infection' black and hiv+ve, segregation. I have never been a prostitute but a prostitute goes out there to find love which they lack, i have never been promiscuous, drug addicts sharing needles If Africans will remove the element of judgment and realize that we're all going to die anyway somehow.</p> <p>I wasn't born here I was born in Africa & I know if I was in Africa the reception I get even the reception it won't be shaking, they won't even touch the card maybe... People generally I think it is a taboo subject. It was confirmed like I said when my, by the experience . For a doctor to just basically write HIV positive as a warning whatever. People are ignorant, I think the only way to de- taboo it will be to do what I think basically</p> <p>The staffs here are all fantastic. I remember the day i was diagnosed the health advisor took time to talk to me. I always remember her face. My doctor too is fantastic. Even though they use numbers to identify us which is undignifying i think it is for confidentiality purposes. My slight concern is when they label even the urine that they take from me as 'danger of infection'. That makes me feel leprous.</p>

					effects that could be used. I would research this first before seeking medical treatment.		especially among us Africans.	
K226AW (32yrs) 3yrs into dx	I was pregnant and ill and had a miscarriage; I was taken into hospital to have a D/C and I had some bloods taken in case I needed transfusion. I requested for an HIV test Had been physically and sexually abused	Picture messages, very useful! They lack picture messages here. I have got loads of written information but not even one picture message. Again picture messages are good for people that come here that cannot read or write. Back home, when you get into the health centre, what do you see? Especially when it comes to seeing a picture of a mother holding a baby suckling; what comes to the mind? Nothing is said but you know straight away what they mean; encouraging breast feeding	Accessing the services here has not been any problem. Er , services in the community; I prepared a small questionnaire; it was about knowledge of sexual/reproductive health services. People don't know the services that are there. It's not until you are sick and diagnosed that you become aware of these services. They offer you massage as well.	Did not share results with anybody except the minister at the Methodist church Have not told my children but I know they know b/c i don't hide my meds. Children in this country do a lot of research & I've got internet @ home. Don't want them to be worried, can share with others.	My meds are my saviour. I have had massage offered in the community. I also received aromatherapy and it is very good.	My host asked me to leave as she could no longer house me after discovering that I was HIV POS Met and married another man who started having an affair with another woman, typical African!	Africans don't come here in this country to get free treatment for HIV. They come to look for money and better the conditions of their families' home. That is why they will not show up in the hospital when they are having symptoms until the condition becomes unbearable.	Hospital HIV services are ok. Staff here are fantastic to me even since I stepped my foot here. My consultant is like my father. People are unaware of services in the community. Its only when you become a patient that you are directed to community services but the info received here is not adequate. They lack picture messages. Many pts are Asylum seekers from African & in Africa we are used to giving health messages by pictures. That is a handicap here. Picture messages are absent. Even some white people speak English but they can't read.
A309AW, 32YR Old divorcee 2yrs	Was very ill on life support machine. Had symptoms that were not responding to treatment. Tested during this sickness episode at King's college hospital but I move here. Had done HIV test 3x b4 and was negative. Chose clinic because i was given accomod. in this area	I think sometime I am confused when I am confused when I read this thing, yeh; I'm confused	Toxoplasmosis in the head. Need some one to go to Africa and talk about HIV properly. Explain why you have a couple, one is positive, the other is negative like me. My boyfriend is still negative. In Africa you can understand the double life, what happens here?	I told my sister, boyfriend and my daughter. Didn't tell my sons cause they were too young and i don't want them to worry. Hide my meds sometimes from strangers because i don't know what they will think but i tell my friends who are close to me i'm +ve & if you want to go you go.	Conventional RX not good bcos it gives so many side effects for me. I only take it bc of my children. I'm born in the village; I always use trad meds. I've got some trad. med that makes me strong. I believe in prayer too. Don't trust conventional treatment. The people here always send injections to	I look different but you know, you are from Africa, you know how people talk. That is the prob. They think it is black people illness Cant take you in a job here with hiv	In Africa, when they say you have HIV, people think the next day you will die. In Africa, we don't have support & that's why people die. Double lifestyle in Africa My boyfriend left me.	No body knows me here & i don't care what happens here. I just pick up my tabs, do bld test and go home. Last time my doctor gave me info which confused me b/c she was asking if anyone in my family has cancer but i don't want to hear that. If the tablets give another bad sick, why are we drinking it. I don't really understand the information here the way English people do because it is not written in French.

				I told my mother and the rest of my family.	Africa for illnesses they don't have here. They send us injections that give us hiv b/c if HIV was truly transmitted by sex, everyone will already be positive.			The first day I came to doctor M. she told, I was with my sister. She said two yrs timeyou will died. My sister was angry with her...say why are you talking like that; you can call me alone somewhere to say this and you don't know what can happen . I'm not scared of that. I'm not scared for that because I, I know I am not going to die now..
I227AW 29yrs old,	In response to a letter sent by immigrat requesting for health check including HIV. Pregnancy checks at GP	I get information leaflets from clinic here but I don't read them	No. I was not sick, only the pneumonia.. I had god fire on my side too and it all dry up but they did not say that I have HIV in Africa. It was something spiritual and my church was also praying for me and I got well. pneumonia	Told my church pastor and prayer group	I trust in god for healing I will try anything that will make me well if really I have sickness. Back home people use traditional medicine and some are well but I don't know. Yes if I am home I will try it because this medication here make me sick. It has too much side effect. But I am just obeying them to take it.	I see many African people here, many black people but I don't know. Anyone of us mind our own business; We just take our medicines and go	End of life	I just come and they do blood test and the say nothing. I come back and they tell me how I am responding.
E1310AW 30yrs old.	Referred from ante natal clinic but prior to getting pregnant, experienced weight loss, loss of appetite, dizziness, colour change, sleeplessness. GP said nothing was wrong Had tested -ve before back 'home'	Have received much written info but can't take it home bc i don't know where to keep it. Don't want friends to see it (p8)	Educate black people to clear away the mentality that they have. Maybe if the NHS can not do it, think of a TV series. Could not have come forward to test voluntarily because of fear. The way the media portrays people with HIV on TV, the way they look. I can't just get myself to come and test	Only husband knows about diagnosis. Don't want to tell family because they will worry. Telling lies about not breastfeeding the baby to hide sickness identity (p9).	Believes in traditional medicine and will take it at any time. Believes that it is traditional med that help her to become pregnant so she trusts it. Also believes in God for healing. Believes in conventional med	My African friends will ostracise me if I tell them	It is not a good sickness. It is something and it is shock. You are jumping from man to man.	Everyone at the clinic is good and even the black nurses working at the clinic (p5).

Appendix 8b: Block and file analysis - Group 2 – CW

G3 CW	Reasons for attending clinic	Sources of Information	Knowledge about HIV/assoc infects	disclosure	Therapy sort	African way/black people's thing	Perception of hiv	Quality of service
M239CW 50yrs old	Was receiving RX 4 bld clot, developed vag. Warts and then sent here for bld tests. Referral to clinic, clinic closer to home.	don't like media bc they show half dead black people sending fear messages which makes people not want to come forward.. Raise awareness using black media channels, black newspapers, black magazine. Using general media only portrays negative messages Put it in centres frequented by black people. The white man is not interested in a black man's health The info here is very good, ID (CD4) count, that was a bit hard to sort of digest because you're thinking what's going on here, you know, what's all these counts and then they sort of, Dr B is very good at explaining things so, information, very good .. Information very good but destroys written info for confidentiality purposes (p11)	Unrelated embolism You see I don't take drugs, I mean, years back when I had my son, I had like blood transfusion, they gave me a pint of blood, but I would never have thought that would have happened bcos it probably, it would have gone onto my youngest child, so I didn't think of anything like that. Erm, another thing he was, when he had high blood pressure, I think years back, he had the wrong treatment, they were giving him the wrong tablets, so erm the tablets he was taking at the time were for someone over 65 and therefore his erm his pressure was over 200, so he was really living on deaths door and what happened, the blood vessels in his eyes burst and he was passing blood, he didn't tell me so you can imagine we had sex, then I think oh my god why am I bleeding! Not realising that it was, what was inside of him, so that really, so I'm wondering whether he had that long term, and he didn't tell me and bcos of that blood that started it off, when I've had infection and I said look you've given it to me, he said oh I've caught it on the toilet seat, and I said to him look don't be so silly, you cannot catch things on toilet seat cos the air that takes it, is going to destroy the bacteria whatever, so he thinks I'm stupid, in that I was stupid in that respect. Erm, so you know there is no other way, I think at that particular time generally you know like when HIV first came out when someone died of AIDS, they bury them in a coffin and they seal the coffin. It was like a plaque.	Told my husband but can't tell my children. Cud have done so if younger. Don't want to burden them (p3). Don't want anyone else to find out I didn't want to burden them down, although I know understanding is alright, its going to be quite a shock and I don't think deep down that erm, especially my daughter, my eldest daughter she won't be able to cope with that, and my you know, my children my boys, they won't be able to cope with that. Not that they wouldn't be able to cope, I want them to look at me for who I am their mother, I want them to look at him for who he is, their father. People talk too much and I don't want to end up like that poor lady in church when the pastor announced	Conventional therapy. Faith in God Herbalist(p7) Massage (p11) I would but I wouldn't stop the tablets but I would see what effects it has. Because herbal remedies can do a lot and prayers can also do a lot and god can just change things. If you ask anything in his name I'm aChristian and I do believe very, very strongly that he will answer.	With black people just tell one person and they will go wild (p11). Black people always in denial Shame is a black man's thing. Black men are ashamed and proud (p9)	A curse Portrayal of half dead people as African AIDS victims. Is it really AIDS? Say it is lifestyle – polygamy! Why are Muslims with 4- 5wives not having it?(p7) People, look at HIV same as AIDS. They don't know the difference. Even though I did the course and everything years back, when I found out I thought it's going to develop into AIDS and I'm going to die. That's why I asked the doctor	Very good at the clinic right from the start, good experience, professional people. if I have to say anything, sometimes I wait a little bit too long but that's natural, bcos obviously they do explain well somebody else who's just been diagnosed and they're going through problems, so therefore sometimes your wait might be a little bit longer. when I look at this clinic, at first when I used to come here, I'm thinking oh my lord, look at it, you come up the stairs every body knows where you're going to, when you're pressing the buzzer to the 2nd floor, they're thinking, you're either going to visit someone, you're either going to the sickle cell section or you're going to the HIV clinic or STI clinic but straight away, my mind works every time, and when I come up those stairs, even now when I'm coming and I see loads of people, I'm thinking lord, I just hold my head up high, and I'm not looking left, I'm not looking right I'm not looking centre, so imagine me at my age, you know, which is a dreadful shame, There's no embarrassment checking out your body. There's no embarrassment in the truth.

				her condition.			'how long have I got to live?'	
G309CW, 32yrs	Persistent cough x 6 month. Came here to test bc partner was dx	Yes I have learnt a lot. They gave me leaflets and I have read all of them, I have also gone to the internet. That was the first time I went to the internet to look for information. That is the bad thing about it that if people haven't got it they will not go into the internet to look for information. When I read about it I got what I need to do. There are many information leaflets in here on the shelves and anyone can take it.	Getting tested is scary. Not easy to tell someone to get tested. HIV prevention needs to be taught in school. The thing is that people don't know the difference between HIV and AIDS so they need to be taught that there is a difference between them. Nowadays some people understand more about it, some are ignorant about it and some don't even know about it. There are some who just stand up and go to people and say I've got it. There are some who still believe that they can have it by sharing a cup or a spoon...I think a lot of people do not still understand what it is all about. To be honest, I was talking to this friend of mine who is a nurse about this HIV. I said why you can go and work with HIV patients... 'No I will never work in such an area. Then she said, I will never treat people who are HIV. Then I said to her, you have been treating other people with other kinds of illnesses, why can't you treat people with HIV; she said I don't think I could stand it. All comes to the nurses as well. They need to be taught; everybody needs to be taught about it. They need to understand more about it.	Shared results with partner and sister. Don't feel comfortable telling parents	Conventional treatment	Dead sentence. How much longer to live	Prostitutes. People sleeping around carelessly when I first came here, my heart just went and the atmosphere just changed me. That's how you feel when you just come through and you think what if...how long will I have to survive. When you have counseling, that is when you know that at least I can take meds.	My partner was born in this hospital so he grew up around here so he is scared that someone will see him. He used to say, oh let's go through the back of the hospital. I don't want to see people. Just that feeling, I don't want people to see me because they are going to talk about me so it is just that feeling., Some really want to be tested but I think coming to the clinic here needs some amt of courage. Maybe if the clinic was treating other things, people can feel free to come but bcos it is isolated, it is something else. When you are coming here, once you get on the lift and press no 2, if there is anyone on the lift they start looking at you because they think you are coming here especially when you are a black person. If there are other wards here people will not know but because there is only, I think only one other clinic at no. 2, everyone seeing you here, the first thing that come to their head, this one has AIDS.
E-11310 CW	Routine test, no suspicion. Had partners who have children	They spoke to me about the medication, about what to expect. They explained to me what the procedure was and what will be happening, when I start my treatment I was talking to the nurse specialist who was guiding me and that sort of thing, telling me how I can manage myself with the illness. I think I've got enough of what I need to know	They were all married men and I did not really think that they could have any type of illness like that. I did not really think that I was at risk at all. To be honest, I did not think about the condom. You know I do not even like the condom and most men don't like it too. Well I asked the consultant if I've got HIV or AIDS and he said to me, 'no you've just got the virus, you haven't got AIDS' and he explained to me but I've never had er.. the thing is that people get confused between HIV and AIDS. The consultant explained the difference to me.	Told two of her partners who tested -ve but the one she never saw the one she suspected. Told husband 3months after diagnoses.	On conventional Rx but would try traditional tx as this exist in the west Indies. Would take it if it works to stop taking tablets.	I mean when I come here, the more people I seem to see are Africans. I don't see many Jamaicans here.	Sleeping around, danger to others	Receives excellent services at the clinic. 'I don't have any problems at all. Some of the nurses have been taking my blood and no one has ever behaved funny or anything like that. The clinical nurse specialist, I mean x and the others there are very good. I've a lot of support from them. Yes theyhave been very good. I can't complain. I have never felt that I am different from the way they treat me.'

		added to the information that I had before. There is lots of papers here with information and I have read most of them.. I use the internet a lot more and i know a lot more about HIV now.						
V23310CW-42, carer	Transferred from Birm'gham. Where she was receiving Rx. Went to see the Dr in Birmingham for rashes coming out of her 'private' and abdominal runs.	Have had a lot of information from the clinic	<p>Unless it is something that's gonna mark you out immediately they can't test until the body is tired and can't take it. That's when they realise they have it. It's when they are dying that they are tested but it takes a lot of medication before they recover or die. That is not good for us who are ignorant. When you test and tell them they say you are the one who bring it home. And you begin to have trouble at home.</p> <p>They feel that they are healthy but how can they be when they have not tested. It is only the test that can guarantee your health. I just laugh at people who think they are healthy bcos they don't know what they are carrying. They have not tested and they don't want to test bcos they don't want to know.</p> <p>As you said bcos of the stigma thing isn't it but people who don't have it would say, pass it on when they touch you, when you laugh, when they kiss you and things like that. But now I know the sickness don't pass on like that. Sex is number one for you to get it.</p>	<p>Told partner about it. Did not tell sister till Dec gone. Did not tell friends because she didn't want friends to start telling people she has AIDS.</p> <p>Can't tell son b/c he is just 17 because she doesn't want him to be disturbed but plans to tell him when he is 20yrs.</p> <p>Hasn't told mother bcos she doesn't want to send her to her grave. She worries even when one has headache</p>	<p>On conventional therapy. Know about traditional med but doesn't know if it cures HIV. Will not take it for fear of any reaction</p>	<p>Some people say it is sickness for African people. I see many African people with it in Birmingham. We receive treatment together. I used to go to some clinics in Birmingham and there were a lot of Africans and as I said, the Jamaicans don't like to come to hospital. I don't see Jamaicans but I see many Africans. Here too I don't see Jamaicans but I see Africans, plenty of them especially women</p>	<p>They know it is very bad illness and it's people who go after women or men that get it; them prostitutes or something like that.</p> <p>Some people think that it is punishment from god and when you get it you die.</p> <p>First when I was diagnosed, I thought I was going to die within a few months but here I am still alive. I hear that many people are dying in Africa.</p> <p>I used to hear that people that have AIDS and HIV they are people that just go</p>	All staff at the clinic are good, making patients feel like a normal person again.

							around and around	
A19510CW	Was pregnant and they found out during antenatal screening	Yes the give information leaflets. Any information they give is useful.	Well that I had HIV! That's it! Finish. It was like i was dead, then i met B..... and he said HIV no longer kills and that i can die from something else not HIV. Because it is just HIV, You don't have AIDS or whatever.	Did not even want to tell partner bc she did not know how she got it so she did not know how he was going to take it	I had a massage when I was pregnant..I really liked the massage, yes it was good but I just don't feel like doing it but it was so good to me my mind my soul, my partner said oh you gonna take off your clothes in front of somebody to get a massage.		It's a dirty illness, I just think that it is something that can happen to you not because you are bad attitude.	They're really good, they don't treat you like somebody that is sick or whatever, when you come in the nurses just talk, laugh talk about your family how are children. I have.....but they don't make you feel sick, they treat you just like a normal person
C-23910-CW (41)	I had this skin condition thing, how do they call it, this condition thing that was not going away. Me complain to my friend, she look, she tell say, I come to the hospital, to NPH here. When me come they send me here and here they come tell me say I have to do test, test for HIV. After test, they call me back say, I have HIV.	Yes she tell me the procedure here and what to expect when me come to this clinic. I think pastor can talk and people will go do test. There is nothing on television and me, me don't watch any AIDS programme so television cannot work very well. I have had lots of information. The nurse give me some leaflets, some papers and the health adviser talk to me about my medication, things like side effect. She talk about the different regime, she talk about sex; she cover everything.	I am happy me doctor tell me say my sick still HIV. Many people don't know the difference between HIV/AIDS. The minute they hear you have HIV, they think you have AIDS, they think you are dying. I have only the virus, i don't have the AIDS.	Sharing my diagnosis? That is not something to share, no man! I cannot do that. I did not even tell my sister, I haven't even told her yet! It is two of us sisters live in this country. It's a secret. I no want she think me careless..	I know about traditional medicine but I can't have it here, I mean I can't have it in this country. I haven't been back to Jamaica since 2 and halfyears now. If I go back to Jamaica, I may try it because, I know there are some bush in Jamaica, they use it for skin condit but I've not been dere. Some use it to bath with, some you eat and some you put on the skin		They think it is a dirty illness. They think it is prostitutes that get it. They don't think they can get the illness too. Everyone have sex so it is not like some people buy it from the market.	The nurses are ok, the doctors too are very good. First time I come here after my test, I don't want anybody to see me but now I am good hmmm, they treat you like normal person. They make you feel ok. They touch you, they take your blood and they give you number to call if you worry about anything.

Appendix 8c: Block and file analysis – Group 3 – CM

	Reasons for attending clinic	Sources of information	Knowledge about HIV/assoc illnesses	disclosure	Therapy sort	Africanness	Perception of HIV victims	Quality of service
W2312CM 45yrs	Had symptoms. Checked at a private clinic and when they were +ve came to this clinic for further treatment. Was exposed, fever, chills, night sweats, diagnosis as confirmation	It didn't make me feel better when I was asked those very personal questions because I had no idea that, that was going to be part of my future. Yes, so I would have liked somebody to have told me on day one; I mean, here this is what is going on, this is what your experiences are gonna be like, this is the kind of information that we are going to need and this is why we need it but nobody did that.	I had no idea about PEP. I learnt about that afterwards when I had been dxed. Had I known about pep, I would come straight away but I knew nothing about pep; but since I was dxed I have become more educated but at that time I knew nothing about it when I was exposed so I had to wait to see if I was infected or not. Diabetes.	Told a few people and friends but not partner. They gave me meds in a brown bag a brown paper bag from pharmacy. I have since been identified by somebody else in my life by somebody else bcos they saw that meds in my home but I found out they were +ve themselves and that is why they knew what the meds was for when they saw it by accident in my cupboard Every time they see your face when you are walking into the GUM clinic; every time I come here I am thinking, what if I meet someone I know and they ask me why are you going to the GUM clinic,	Buddhist, mystic powers, chanting . Conventional therapy. I'm master of my own destiny. I have the power to affect my own life in a positive way. I have come to Buddhism only in the last few months and it's been very beneficial to me. Even though I'm late for the clinic today I had to stop to chant before I left because I knew it was more important to be late than to miss chanting opportunity. It is very important to me. If I don't do that every day that day might not go as well as I hope. It is very, very important to me.		Not sure because I have to look at my own experience back. I thought it was a death sentence. Bcos they are afraid of what that means for them with regards to 'a dead sentence' and, and also being a part of that stigma that comes with that. I couldn't be as comfortable in the way that I socialise with other people. I am aware that any encounter, sexually, any sexual encounter could lead to disclosure for the other individual so that was something I was very afraid of.	I was surprised that problems came afterwards after coming to this clinic here. Was very shocked at the laissez - faire attitude of people here. It was deeply upsetting. I got the impression that they expected I was totally comfortable with my diagnosis so I was not told. There was no time taken to even talk about whether I was or wasn't positive. I was totally unaware of the subsequent meetings and the intimacy of the questioning. And I also was very, very concerned with the sensitivity or lack of sensitivity that was around it; talking about my personal life such as infection and that I wuld come back and they wuld ask me; 'have you had sex?, who with?, were you active or passive?, what role did you play and all that sort of questioning around my sex life; They referred back to my GP on what I was having for my stomach complaint wrote there that I am HIV known. I never told my GP. My GP contacted me and arranged a meeting & told me 'I have been made aware from the hospital, NPH, that following your stomach exams, you are HIV positive'. That was another conversation I did not expect to have with my GP and again it all came through this clinic.

G217CM 43 yrs old	Collapsed in America Sick, emergency RX, toxoplasmosis in the brain, brain operation, no options, collapse, loss of weight, changes in appearance Mandatory test on admission into hospital in the states. Close to home. Wanted to be treated with steroids and not surgically. Steroid option not offered to me in America.	Written information given out at clinic. This is not useful as many people attending the clinic cannot read, They are informative. They say exactly what they have to. They give factual information. How can you give somebody a form to read if they can't read? You explain that to me! If I can't read, again, am I going to tell you that I can't read?	Toxoplasmosis. it is now more prominent than any other thing; prevention, cure issues, ways to go about it. I think it's like in the States it's like a commercial for young people and they're drinking, they show gonorrhoea and all these things, you know. Sexual d'ses even with all of that, the reality, that's why as I said in most places, clinical places like this, and even the gov't, they get it wrong because they work by statistics. They don't work by the individuals or by the people.	Well, my mother was there and other family members were there when they gave my diagnosis because I said I collapsed, so there wasn't really much choice.	Traditional medicine, exercises, aromatherapy, massage.		Room for improvement, improve approach, user friendly approach, gov't gets it wrong, working by statistics, don't work by individual/people, already worked out strategy, one size for all, decision makers, see reality, information to read, staff polite, like waiting for the bus, ridiculous phone system ,unmanned reception, It needs to be manned 24/7, can't call to make apptment, can't have certain advice. Disappointing apptment system, This place needs a lot more improvement in terms of the way, in terms of approach. Service needs to be more user friendly in terms of approach. Listen to what the people you are treating have to say. So that the person doesn't lose their dignity, you're not demeaning that person so giving that person their integrity .
C309CM 40yrs old	I came here bcos I was having like Sort of genital boils coming out on my penis, and I was very concern about them so I thought I shld come and get checked out	I have just been taking lots of information leaflets from the clinic here. I have just finished reading through all of it. I still read. I keep reading them over and over again and what I don't understand and whenI do	It seems like at this present moment HIV seems not to be so important bc you hardly hear a lot about it in the media. I remember when the HIV/ AIDS came out and I remember, there was adverts on the TV 4x evry single	Share results with partner, can't brave it to tell someone, can't tell family, secret to live with. Tell me you have sugar or something or any other medical prob, I will be able to share with my family and friends not hiv; . It is a bad stigma	Conventional treatment. I will give anything a try to get rid of this, any medicine to get rid of this HIV from my body I don't know, I believe, I guess I believe in traditional	I don't think I need HIV test, believe they can't catch it, eat right, because they keep fit and especially if they don't see symptoms , they won't came for HIV test. The worst thing that could happen to	In the black community although it is all HIV, they dismiss HIV. A lot of them go straight for AIDS. If you've got HIV, they say oh! AIDS. At first when I heard the news because I didn't know much about HIV I thought 'I've got AIDS and I am

	<p>in the clinic just to see exactly what was going on, and When I came to get a check, the doctor said 'would you like to have an HIV test</p>	<p>come to the clinic I always bring it up. I am learning more and more about HIV each day and understanding morebcos you know, I'm always picking up literature about it and reading more and more and on the internet as well learning about other people's experience and so on.</p>	<p>day on evry TV channel. And maybe if the govt cud push it more on the TV & in the media it wud help people come forward to have the test .Did not seek help bcos the boils were, at first, in the first year, they came once, hardened so I thought it was only the friction there or something and I remember the 2nd year, the site, well it came back 2x for that year, 2, 3 times and that is why I started getting really concerned bcos I said, what is this thing? And then the 3rd year, it started to come once every three months so by then I said to myself 'something iswrong, let me go and get checked out at the GUM clinic' That is the only reason why.</p>	<p>thing</p> <p>something that I couldn't do, go and confide in somebody that i have got it. yes, for the reasons of the stigma behind this disease. I know what my friends and my family think about HIV. I have heard them just in general chit chat that erm.. That it is something really bad tothem. Even before I was diagnosed, I used to be like them. I am sorry, yeh I used to be ignorant like them yeh, but the reason why I haven't shared it with them is that I feel and i definitely know that I will be shunned. They will keep their distance from me. They give you a cup of tea and when you are not seeing them, they throw away the cup bcos they can't reuse it. I 've heard so many conversations about HIV in the past and like I said, I used to be one of those ignorant people and I have heard people say such and such has got HIV and they work in that</p>	<p>medicine and I want medicine.</p>	<p>a black man is HIV.They just think it comes from African men or African women; just from black people. it comes from. Condom but it seems like they wouldn't use a condom if it is somebody else because they think hiv comes just from African people.</p>	<p>going to die.</p>	
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				restaurant and then nobody goes there .				
E086CM 42 yrs old 2months into diagnosis	Chicken pox. Fishlike scales on the body.skin things' coming to your body. They say it's, if I have chicken pox it should take two weeks to heal but instead I noticed, I went there in February, March it was just accumulating more, then and I said no, this is not chicken pox. This is more than what I can handle so , they refer me to a dermatologist and they say that it is psoriasis, skin condition	I just ask question the treatment, what is it if I want to have it. They say no because they want to see, they take the blood test so they can tell how low my viral system is, how far it is dung. If it is hup or dung, if it is way dung, that means I have to start the medication.	Syphilis. Does my body going to take the treatment well or does my body going to reject it? And if I take the treatment, does I going to get much sicker? Or my system turn, actually I don't know. So that is how, that is the first thing that come into my mind, nothing else doesn't worry me at all; the fact is that I have it, i have the sickness. I think if I was doing the right way going, having safe sex, having sex with condom, this, then this wouldn't happen. When you don't use protection, you are likely to have any sickness, Anything can be happen to you so you have to be .. ceafur,... my advice to peoplewhether young, hold or what: always make certain that you have the condom, in everything that	I don't tell anybody; not even my mum. because my mum is a person like this, the moment she hear something because it's us two kids she have; , this thing, I keep to myself, I don't share; that is privacy	Not yet on HIV RX but on conv'nal Rx for syphilis The only therapy I know is the 'bigger man' upstairs which is god and that, all things impossible to mankind but sometimes god can do things you don't know bcos we don't hold the future. I hear about trad medicine but i will not try it. Here they come do me blood test. Trad med don't do blood test, so you don't know if your immune system up or dung. I know herbs treat small sickness. I don't think it treats ting like HIV. massage	Most of us,, the black, the Africa, theCaribbean, they have this little stigma "pride,; we have to put down pride bcos pride is a thing that can be downfall you and beset you. Its like in Africa I mean when there are people there who cannot afford it you know; sometimes it hurts, it really hurts to know that sometimes your hown black brother or black sister dying and they cannot be reached but the real thing ispain, it hurt deeply in, the thing	People which have this stigma about HIV people, come on, wake up	It is good and they treat you well and they refer you also. information is good and detailed.... everything, dung load everyting right to the nitty, gritty

			they do, have the condom.					
T239CM 38yrs old	Regular routine testing, diagnosed on routine testing, the nearest centre to my locality to where I live	Has received lots of information in the way of booklets. There are magazines on the shelves and you can take at any time.	They were little white tablets. I also noticed certain rashes on his body at certain points, which I had when I was diagnosed which looked exactly like hers which I thought amazing and the same discolouration, and some very bright patchy yellow skin coloured rashes. I brought it up to him and he said he didn't have it but I knew I know he had it because he was the only one I slept with before I was diagnosed. It's like if it was something I slept with say more than one person then I'd have to look at other people but all my years I have been checked	I've spoken to my sisters, but not my mum and they are all shattered. They took it very badly, they were very upset, very upset, they couldn't believe somebody would do that. My sister said to me oh you should tell mum but I can't because mum is not very well, she is diabetic, she's very ill, she's under the care of social services	I would say no, the reason why I say so is, traditional medicine I believe is good but for something like this, although it's a virus, I, I look at it as being a primary disease, erm it can develop into a disease if not dealt with correctly		They think it is a promiscuous, self gratifying disorder. That's one of the things that I think needs to have like a parent focus where the parents need to know about infections where for example, they could be able to say that child has been diagnosed with this. It is not a dead sentence	Ok, the experience has been very good. They are all supportive. They like you to be on time, don't be late I would say yes and just looking behind you, that is quite new. It looks all ready to pick up
L1612 CM 45yrs	Sickness, toothache, mouth odour, pain, tiredness, sleepy, leg pains, back pains, back rashes, collapsed,	The lady told me she was counsel. I don't know about counsel but all I know about is that she was trying to make me admit that I've got that'd be in the first place and I wasn't	I always think that it will never be me; it will never catch up with me because I don't go with prostitutes. I don't sleep with any girl who only talks to me. Sometimes we only kiss and that's	This is as worse as it could get in my books If I get a new partner I will look at the circumstances. If they permit, I will tell her. Not tell partner, keep it my secret, will not	Self over the counter medication. Conventional treatment. I have not taken any other form of treatment	The thing is that the living that black people are living here is more tougher, more tougher, rents, the living in, lifestyle has changed and become more	Disease of prostitutes - no go area The reason why I allowed them was because I wasn't in the mood arguing anymore. I was dying. I knew something is terrible wrong so I had	Really helped, pleased with service, truth, honesty, free service Everything is done for me. I can't complain. I say everything is done for me because I have not been sick like before and also when I came in I was pleased to be receiving the services I've got. I know that some countries, you have to actually pay for your services and this place is actually free

	<p>couldn't get out of bed, shingles. Brought by ambulance to hospital. Referred here from ward</p> <p>Painkillers, mouth washes, stronger painkillers, changes, running stomach, bad health, body pain, very serious, get worse, not ordinary, chin rash, weight loss, body weakness, headaches, sore intestines</p>	<p>buying with it until she went & printed out the proof a week later. They give us some magazine, some papers but i dont even read it. I dont want to know. The onlything is that, I am getting better. That means that the medicine is working yes it is working. If I need to know anything I ask them, I ask my doctor.</p>	<p>it and she go her way and I go on my way. Even with condoms, i don't even want to use them. Because I don't like condoms, I don't want sex at all.</p> <p>I was surprise to have the HIV in the first place. I was surprised bcos I was staying away from all sort of sex; I was minding my own business. If I've got it, it could be by a mistake somewhere or maybe I have kissed somebody who has got that HIV, Who has caused that, that thing, but, but for the doctor to actually explain it to me properly, it means that I've got it in about 2 – 3 years back but I think my immune system was strong, fighting and fighting it until it was getting worse; At first I thought that when somebody, you know when HIV first started; you have to see the person very</p>	<p>tell new partner, no reason to share diagnosis, not lying to anybody. I don't see the reason why i should share my diagnosis with anybody. I've got no reason for it.</p> <p>I have to wait and see how I get on; and getting a partner now because I don't want to come clean about it. I don't have to be clean with them and stay together with them, that's it period! I mean we can share things in common, like we can share jokes like friends, like we can look for something to drink but me..... but to share my secret with someone, no, no, no!</p>	<p>tougher. Now people don't want no more to share anything so that is the onlyproblem. They don't want to share anything because it is not necessary. You tell your friend a story, the next day it is everywhere. People no longer want to share anything. To me that's the only problem. The living standard has changed as well (coughs out loud!) but that's what makes the people not want to share accommodation. You know a lot of people died as well because since the last 5 years, i have been to some funerals for people who have died with some persistent problems.</p>	<p>to relax. I had to let go too.</p> <p>Those who have had it (coughs out hard), I mean HIV, but I was thinking it was mainly between prostitutes, those who go out to sell themselves. Now that is what I was thinking about. I was thinking, like, someone who actually is having health problems, then I wouldn't go near the person at all. When, before i became ill, i think about it very less often.</p>	<p>so in my case i was very pleased. The way I see it, they really, really helped me out. I am very, very pleased with every service they provide because they came out and told me the truth. They always treat me with honesty.</p>
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			strange, strange disease. Then you will know that this is a no go area . Now I didn't realise that even though someone is playing football, still they can have the virus life. Now I have got a different perspective of it, now I can put things into different perspectives (coughs) and because now I know that everybody can have the virus as well					
R-212-CM-NP2 50yrs old	Routine health check. I just came one day to take a blood test and that's how they found out that me have de sick. They say me have the HIV. - Me, I receive plenty of counselling from that lady, What them call her again like that..erm, health adviser. Nurse them	Them give me plentyof information about me sick and how me fit remain healthy. You come, them talk to you nice, them take your blood. Can't complain. Every thing good nurse. Fear to know them get that sick. Plenty black people say them can't come forward to test. Them fit well till them fall sick. Them fear that stigma, some fear to die. Them think when you	No, just one woman. Me always together with her but we don't have sex. We never sex, she is me good friend. People think me have sex with her because me and her very close. The highest thing we do, we kiss. Me tell her to come test butshe too negative. So me not sure how me get this thing man. When me want to sex any woman, me use boots.	Yes my wife and me friend	Not yet on treatment. Yeh man, me ready to take anything to get this thing out of me body.	African people too, them get thesick too much	It's prostitute them get the sick.. People them have the sick, they, them die you. Woman I go to have sex with, them not prostituteand me use them thing all the time. That is why me tell you say, me think that boots burst man. Them think once you get them sick you dead.	Very good, the nurses, the doctors and everybody them good. The receptionist and everybody. Them give me plenty of information about me sick and how me fit remain healthy. You come, them talk to you nice, them take your blood. Can't complain. Everything good nurse.

	<p>and them docta who see me when me come here give me plenty information about my sick and that tablet. Me not taking tablet yet. Them give me plenty of leaflet be can't read so much so me, I can't take the paper.</p>	<p>get them sick, yeh that's the end. Me think the same nurse until them dx say me get the sick. The doctor & the health advisor talk to me. Them say look here, say me get the HIV virus not AIDS and if me look after me self me remain with HIV not AIDS. Plenty people ignorant.</p>						
G-10910-CM	<p>I was having fever and cough. The cough stop and go and come back. My chest just full of stuff. Sometimes I have diarrhoea too. It come on and go and come again. I am losing my weight too. I am trying to eat but I don't feel well most of the time.</p>	<p>A lady talked to me about what happens when your results are +ve. Yes, I can say that was counselling even though at the time I did not see it like the counselling. I was not interested in her stuff; the stuff she was telling me. I knew I was not +ve. But then, when I got the results, I was shocked.</p> <p>I think coming to the hospital is a personal thing. You cannot force people to come out and test.</p>	<p>I did not suspect that I could be HIV pos bcos they say HIV is for people who sleep around carelessly with women</p> <p>I will advise them to test, not to do self medication because the problem will not go away. The earlier you test and know your status the better for you. HIV is not AIDS so they should not be afraid to come for the test. Before, I used to think that HIV is the same as AIDS but when they dx</p>	<p>I don't know but I am not ready to tell my girlfriend right now. She is not sick. She still look alright. Will not tell any other person even family. Have much information in my house that they give me here. Don't keep in the open. Don't want anyone to ask me anything</p>	<p>I have heard of tradit med but have not tried it. I do not think it can work for HIV. HIV is a very big illness. I think using trad med is only trial and error. I have never tried it before even for another illness.</p> <p>In the past I have taken cough syrup that I buy from the chemist, medicine for other thing like pains and when I have cold too</p>	<p>Some think that it is only black people who have the illness; only African people. I also think that it is an African, an African thing bcos you have many Africans who suffer from it. You've many in the clinic here and they say many people die in Africa of HIV/AIDS. I think it is an African thing because almost everybody have it</p>	<p>Some of them think that it is the sickness of womanisers or prostitutes. Once they hear that you have the illness, oh he was sleeping around with all them prostitutes. I meet some of them here at this clinic. I think that people that have the HIV are people that go after the womens. People think that once you have that HIV, you have AIDS and you are dying. Me I use to think the same.</p>	<p>I am beginning to get used to it. When I was newly diagnosed it was very difficult for me especially coming to the clinic here. You know because this clinic is for the HIV patients, everybody know it. As soon as they see you coming this way it means you are HIV. So at first, before coming towards this direction I will look round to make sure that no one sees me coming in here, yes it is very difficult but I am beginning to get used to it</p>

	<p>Immediately you bring that kind of topic people think that you are judging them and some people are not very happy about it.. But I think you people as people who work with HIV can advertise it on newspaper or on the TV</p> <p>I have received so much information. Health adviser talk to me and dietician talked to me. They give you lots of leaflets here like those ones that you have on the shelf behind you.</p>	<p>me, they tell me HIV is when you have the virus and AIDS is when the virus has already attacked your immune system and your body don't have any defence for other sickness; that is when you have AIDS</p>		<p>and they have worked..</p>			
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Appendix 8d: Block and file analysis – Group 4 – AM

Participant	Reason for attending clinic	Sources of information	Knowledge about HIV/associated illness	Disclosure/broken narratives	Therapy sort	African	Perception of HIV/victims	Quality of service/ Access
G20410AM 32YRS,	That's when they discovered that she was HIV pos. when they discovered that she was pos, I was also invited in to do the test and they found that I was also HIV pos & that's how i got to come to this hospital	The media in this country, when it comes to AIDS & HIV, they're not giving as much publicity. There's no enough info. It's now only of late when they're talking of STIs & Chlamydia but they're not actually mentioning HIV which is the biggest threat bcos STI, is treatable but HIV, they must put HIV on top and STI at the bottom. Info on AIDS is not much, there is not much info whether on the TV, even in the papers. Was there sometimes, in early 90s in early days, but at the moment, there isn't much info on AIDS. So it's life or death. If you're dxed earlier with meds, the advantage of the meds which is there, you can live longer.	It is the knowledge of what HIV is. I think the info is incomplete. They talk of HIV but they don't explain it fully. Some people, don't comprehend what HIV is and what's AIDS. Those many people may think of AIDS when there is HIV.. People are now aware of this HIV but what I have seen now is that people are waiting until they get pregnant. We've got a few people who will not go and get tested bcos there is that fear; bcos that time you discover you are HIV pos.	To be honest with you we thought of it. You know we are all from African heritage. At the moment there is stigma about AIDS. It depends the person that you can tell; But at the moment we've just kept it btwn both of us. We've not even alerted our parents It's btwn me and her. You hardly find people who can maintain a secret or keep a secret. They will also want to share with somebody else.	Yes, I wld consider trad med, but will also want to know the properties of the type of med, what it does on ur body. I will need to know more about that med that trad med bcos even the tablets I have got, they come from the trees, but now there are synthetic, they have gone through but I wld also want to know more about them as well. I wldn't mind using them. But also, you will also need to know the side effects, what they do for you along those lines.	But you know the moment it goes, like in the village, in Africa, it will be 'oh they are HIV pos, they're HIV pos. It's either you don't get along well with them or when they see you, you know, there is that look or talk which can affect you in the long run .	They know the disease; whites they do know but I think a small % not a large number. It's a small % and the general perception is that the disease is for black people it's just for black African people is the perception that they have got.	I find this place welcoming; whatever you want, they do it , like I've got S...'s number, I can phone S..... whenever I want; if there is anything that you are worried about she will advise or ask you to come in or whatever info she can give us . We're always at ease. For the Rx I am receiving here, I can say it's excellent. I wld say so far I've had no problem with the receptionists, drs & nurses. Everything has been just, you know excellent
M219AM 35 - 40. 7mths into dx	It was in Jan when my wife went to the GP to have a check up that women generally have when they're preg, they asked her if	You see it was only in this country I came and I turn round and I have never seen any advert on HIV but in my country maybe bcos they're still educating people	Have been given so many flyers, this and that but I have never gone through them. Teach young people how to go or how to protect themselves or how to do this, how to know about it but most likely	I told, first of all I told my head of department in church and his family. .	The only option is to rely on God if I am not coming here, that is the only thing, I don't have any where else to go to, even when my wife is receiving the Rx. well I don't know whether they have all this trad med here, they	I have never tell you that it is What I have, it is what the doctor says. The other person they will tell you I have HIV but to me I	If they put HIV, hepatitis, diabetes all these things or lets say cancer I say If you are wise take HIV, HIV does not kill you, except you kill	The way they are treating us here the way the doctors are so good and the nurses like Andrew, they always call us to confirm, when we started they would call us to ask us how we are feeling

	<p>she wud like to do an HIV test and she said yes, they asked her to bring her husband also to have the test, so I tested +ve too</p>	<p>about it, I think this wud have done a lot about the advert and in schools but there are some young people that have..its not all about what do they call it this sex education in school, its not all about bcos when a young lady is growing up she won't bother about condom when the sexual organ comes;</p>	<p>they have to give them protection but having HIV and AIDS bcos if you're afraid about AIDS but you must have HIV before you have AIDS.</p>		<p>shouldn't deceive themselves to go to trad med, I think even as I say I'm praying about my own bcos I believe our God is a healer and I have faith in him .it's not everybody that will do that, even if I started the Rx I will never be down so if you say you're going to be okay backed up and if you're taking any meds, like now if you are, u've to take one/day, two/day or even three. Taking any trad med I know most of these drugs they get them from herbs but they have no quantity that your bld can take, that ur heart can take in a day /mth / yr but all those ones they can just cook all the concoction & put in a bottle and say put hot H₂O or wine inside and shake & be drinking, so it's good to come to the hosp & know exactly what you've to take bcos they've tests, they've a lot of research here, they've to test with sthing to know the effect b4 they give you</p>	<p>will not tell you I have HIV its what the doctor says, because that's why I rely on what God say concerning my life.</p>	<p>yourself but hepatitis can kill you I've seen my friends that they have such kind of things it does not take up to one week they discover it and they die bcos it has not been discover in time...Ca the same thing, Ca they will give you time you are dying in so so wks, HIV if you are taking your meds you can eat anything, diabetes will not eat what I want to eat, so it is good for someone to check up even though you are living normally, when you know that's when you know how to maintain yourself.</p>	<p>I told you before that the doctors the counsellors they really welcome us, I love the way they were treating us. I have never had any problem anytime we come. All the nurses, they are nice, we chat, how are you feeling they take us like, they embrace us</p>
C1201AM. 2mths into dx, 46	<p>Well I was having a cough which was persistent and some skin problems, losing weight and generally unwell. I was trying to address the symptoms whatever ; went to GP& after which I went to the private clinic</p>	<p>The information I received here was good. We talked about long term plans, say what will happen in two years time, ie my long term and short term goals while I am receiving my treatment.</p> <p>I think the education has got to, although it is hard, it's got to start from schools, maybe</p>	<p>I think we need education amongst ourselves to change our perception of HIV and victims; people need to be aware that HIV is not AIDS. People out there, once they hear you have HIV, they just think you are dying, they think it's AIDS. I used to think like that until my consultant told me HIV is different from AIDS. Our fellow black people have to be educated, they have to</p>	<p>No, well, did not share my dx wit anyone. It is just confidential. I only trust myself. I don't trust any other person with the info. The minute you tell one person, the next minute the community will all be looking at you.</p>	<p>Ya, I did try Chinese medicine. I've had acupuncture as well. They did help but I still had worrying symptoms and thought it is best to see my GP. My GP then referred me to the private clinic. I've had acupuncture but I haven't tried traditional medicine.</p>	<p>when I had symptoms I was always talking to my brother but for most times I was in denial for when I actually found out that, that was the problem I did not say anything bcos then I knew. If I tell especially an African here, the</p>	<p>I think people have still got a very -ve perception of HIV but as for me I know that I can get that confidence from the medical team. They think you are promiscuous.</p> <p>I think that HIV is stigmatising in</p>	<p>If there is anything, the NHS has been fantastic in providing the care and services we receive.</p> <p>I think in terms of assessing Rx it is very fair. I don't know what is done in other areas; I am talking about this clinic whether you are black or whatever colour. I think there is fairness in all they do here.</p> <p>The only thing I did not see</p>

		<p>churches and among ourselves.</p> <p>Ya training sessions for people going to access Rx for any other health condition, so just to make them understand that to have HIV is not like any other disease that you may have. Ya fortunately, it is not like Ca which may be difficult to control. With HIV if your med regime is not working they change it.</p>	<p>be aware. Education shuld be centred on black people, whatever; in the black community giving time to improve their perception and uptake of testing</p>			<p>next minute all Africans will know like in Africa & you'll have no friend. And the family will not want to come near you, they will keep their distance. So, have to keep it to myself, I don't want my confidence to be betrayed; you can never trust a friend with this type of info. They might keep quiet if it is another thing or another illness, but with HIV, no.., they will never keep it.</p>	<p>itself and other people see HIV as a taboo and will not want to think about it.</p>	<p>is info to someone who is HIV +ve in the long term. I have like grown up children; maybe in the future I might consider increasing my family. What are the implications? I don't know how this could be done.</p>
SO87AM (T8) Almost 3yrs into dx-37yrs old CD 16	<p>Referral from mental health department. I was very ill like I get confused. I don't know what I'm doing. For me to come hosp I found it later, bcos I think I was 'fery hill, then after some, some time again I found...even for me to come to the hospital, I don know what happen with me. Then after, I find out that in the hosp that I have this virus so since I came this</p>	<p>They give us many paper information. We go round giving to other people like at the embassy, the shopping centre; But I think many people that we give that leaflet read the leaflet.</p>	<p>Yes, that time I was, that's what I'm saying, I was very, I was in hospital; one of the nurses, that time that they told me, I'm still like I'm going to die or my life, because I don know or; I used to hear that thing in Africa that HIV, but I never take it that for me, I'm going to get that, then I used to know that it's a something like, may be if you get that thing, your life will, you will die. That time they told me that, I was in the hospital so that time I feel so down bcos I think I will take my life so one of the nurses talk to me that 'why is Mr SO87AM always keeping quiet? Stop thinking! Take the medication because many people are taking the medication.</p>	<p>No, that time I was, I didn't talk; that time I was in hospital and my sister - in law, and her husband try to ask me what was the problem but I tell them it is a kidney problem. For that time Dr told me my kidney, I had some kidney problem, something like that, they said I had TB also that time, that time so that is why I'm saying I was 'fery hill'. According to the dr my CD count was 16.</p> <p>To tell my wife, It take me about 6 months, I couldn't tell her.</p>	<p>I have massage. I didn't understand proper. That's why. I've it since I started, I go, I had massage every week and some exercises at St John's Wood. I also go there to the Monks Park clinic.</p>	<p>My sister inlaw asked what was the problem but I tell them it is a kidney problem</p> <p>For me, it started when I'm in hospital, you know when I was there in hospital, you know African people, you know they don't understand too much.</p>	<p>I'm know that HIV is a, is a d'se but we get it from the, the sexual...something like that. The most thing people, me, me I'm know that people still don't understand the thing so they still have to do advertising</p>	<p>Comfortable with the care received in the clinic</p>

	country, I get confused; even for me to go hosp I don know so one day I saw that I was in the hosp; my CD count was 16							
U176AM 50yrs	I was sick, you see, then I came to PRH; it was..13th of March 2007, I think they tell me... one vein of my neck was problem. I came to see the docta. He said to me they might need to check any patient for HIV;	Gets counselling. Given information leaflets	Concerned about the way he got his infection; malicious infection by girlfriend	I contact my girlfriend to come to CMH, she came. My former girlfriend, Then when she call me back she said to me, did you hear something wrong about me. I said no, listen to me. Get down this phone number; I've been dxed HIV positive. Told current girlfriend.	Traditional medicine in Africa yes but I don't know if it treat HIV, I don't know that one. But if I am in Africa, I can try.	This thing they do in Africa, Africa people know that they have the HIV, but they keep quiet to infect other people,. Those things they do bribing people. That is African things not over here but they bring it over here, doing those things but you know that you are infected with HIV .	But many people can't come. They don't have the courage; it's like a dead sentence. It's like you are holding a trigger to your head waiting to blow it off.	They are NHS, but today I do not believe the NHS because of bribery. Some people, they bribe the nurse to cover up their sickness, to issue the HIV result test negative but she is positive. My former girlfriend is HIV positive. It is NHS do things that you do not trust them anymore. The nurses are corrupt, the nurses at hospital D give neg report for my girlfriend and she is HIV positive. I do not trust the NHS hospital any longer. With the nhs everything is possible. When you come you receive RX, like eh Dr M said to me that, if my body does not agree with any regime, they change it to another regime; Even today they can call me like a guinea pig, I will go because I am a human being.
N198AM	Invited to test because of girlfriend's positive status during pregnancy	No, not that I can remember. I don't take any paper here. My English is not very good so I don't take paper. I have not seen paper in French. If I see I can take it.	But now I know that I am have HIV. I was having illness but I don't know I am having the HIV because I think HIV is for people who sleep around.	My brother, I told him. I did not tell any other person, I told only my brother. I don't tell my parents, but my girlfriend is telling everybody that I give her HIV.	I don't think about other treatment yet. I want to see how this one go first. But if there is other medicine that cure this thing I will take because I am not happy that I have this thing.	Me and some other people. we think that is sick for black people, African people.	They think that when you have the sick, you are finish. Some think it is prostitutes who have it	For now I can not say anything about experience. Maybe later but not for now, I don't have any experience. I just come, the nurse takes my blood, I go home and I come next time they give me results. Sometime they ask me to come after 3 weeks. I have no experience yet.
T23610AM 1.5yrs into	I come the hospital because I was sick	Yes they have given me information leaflet	The doctor told me how to live and how to be careful	Only my wife. I don't tell my family yet. I	Traditional med, I didn't take it. No, I didn't take the	I think they use it too much back	People think that HIV is same as	My experience of this clinic. Everybody is doing very

dx 42yrs old	with cough for long time. I went to my GP and he refer me here. I come here with the cough and that chest pain. Before I come, I cough just too much. They say I have TB, oh before I came here, I didn't know that I have a TB and like..eh, they check my blood.	here. I find that information is good. Is enough for me because i have got books that talks enough about it	Tuberculosis	have my family back in Africa but I don't tell no body. The only person I had to tell is my wife, she has to know and they have to check her too so that she can also start treatment if she is positive. I did not have a reason to tell friends...friend can run away from you when you tell them.	traditional medicine at all because I was here before I start to fall sick. I think they use it too much back home in Africa. Will talk to my doctor if I want to start traditional med.	home in Africa	AIDS. Some think that people who have it sleep around	good, the nurses, the doctors everybody is very good. If you have any problem, if you telephone they give you solution about anything. I think this clinic is not only HIV people who come here. People come here for other things. Ok you can find so many people and i think they come for different things.
T3012AM 45yrs old	I didn't suspect anything. I was very sick but I did not think about HIV. Just when I came to hospital they told me, now you can be HIV so....I was very sick, very very sick. They did the hiv test and say it was HIV. I collapsed one day at home and then my wife and my daughter called the ambulance for me.	Very sick when admitted in hospital. Received no information and even no counselling..	I get on the bus with my son to go home; I can't remember where I am going; I can't remember my house address HIV encephalopathy/dermentia and pneumonia	I told my dad back home. Even my brother he knows about it; my sisters; all of them, ya. I told all of them and they are giving me support	I don't know I never tried that one but the only thing I know this treatment myself that took it for years....if you take your tablets regularly you are going to get better. Like I tell you before they diagnose, I lose my head because I get on the bus with my son to go home; I can't remember where I am going; I can't remember my house address. But it is my boy that rescues me..... Now I am better.	I think all hospital care for HIV because is too much. It is the white man who bring it to black people because they want plenty black people have it so they call it black people sick. I don't trust them. They take it to Africa and they say Africa people have HIV. I tell you, they say they want to reduce black people population.	danger for the nation, the younger generation, some of them they don't like condoms at all, I don't like this one like to feel it myself. They know it is bad sick. They think you die when you have it. They think people have it when they go after too many women. My dad has three wives; why he doesn't have it? I did not know I can have it, yeah, now I have it but that time I have only my wife.	Since me I start to come here, I have no problems, the nurses, the doctors are very good. Everybody is good, I can't complain. When I have problem, I ring up here, they tell me to come in.

Appendix 9: Letters of access



GENITO-URINARY MEDICINE & HIV SERVICES
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THE PATRICK CLEMENTS CLINIC Hospital
Watford Road
Central Middlesex Hospital Harrow
Dr Gary Brook - Clinical Lead Middlesex
Dr. Siobhan Murphy - Consultant HA1 3UJ
Dr. Andrew Shaw - Consultant
Dr. John McSorley - Consultant Tel: 020 8864 3232

AS/AB/
17 August 2009

PRIVATE & CONFIDENTIAL

Concilia Ajuo
Main theatres
NPH

Dear Concilia,

Re: Research Study on help seeking behaviour of black Africans and black Caribbeans to diagnose HIV/AIDS

Thank you for your letter requesting permission to recruit participants for your study from the Northwick Park hospital GUM clinic. I note that the study has been approved by the Brent local research ethics committee and you are already recruiting participants at the Patrick Clements clinic. Dr. Gary Brook is your supervisor within the trust.

I am happy for you to access the GUM clinic at Northwick Park hospital to recruit more participants. I discussed this with my consultant colleague here, Dr. Moses Kapembwa, and he too is happy and asks for a copy of the Ethics approval for our records, and also that the consent form and patient information sheet is on Trust headed notepaper.

Perhaps you could come to one of our Monday lunch-time meetings, to give a brief description of your study to the team to enhance awareness and enthusiasm for your study? The other key person to contact is Sara Nicholas, who is our Senior HIV Clinical Nurse Specialist, and knows all the patients very well.

With very best wishes,

Andrew Shaw
Yours sincerely

Dr. Andrew Shaw
Consultant Physician

Cc Dr. M Kapembwa, Consultant Physician, GUM Dept., NPH

Trust Headquarters: Northwick Park Hospital, Watford Road, Harrow, Middlesex HA1 3UJ Tel: 020 8864 3232
www.nwlh.nhs.uk

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Appendix 10: Potential participant letter of invitation



Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

Tel: 020 8864 3232

Dear Potential Participant,

My name is Concilia Ajuo. I am a nurse in the operating department at the North West London Hospitals NHS Trust; Northwick Park Site. I am a doctoral student undertaking Health Research studies at the University of Hertfordshire.

As a course requirement I am carrying out a project which is looking at the "*help seeking behaviour of black ethnic groups and specifically black Africans and black Caribbeans to diagnose HIV/AIDS.*

I have attached here some information for you to read through and understand the purpose of the study and consider if you would like to take part in it.

Please take time and read through it.

Thank you for your co-operation

Yours sincerely

A handwritten signature in black ink, appearing to read "Concilia Ajuo".

Concilia Ajuo

Theatre Sister

Northwick Park Hospital.

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www.nwh.nhs.uk

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Appendix 11a: MAXqda2 Attributes

Attributes							
Textgroup	Textname	Creation Date	Number of coded segments	Number of memos	Author	Bytes	barriers to help seeking
African Men 29	transcript	06/09/2011 12:10	0	0	home	9358	0
African Men 13	Transcript	06/09/2011 12:09	0	0	home	12914	0
African Men 12	Transcript	06/09/2011 12:09	0	0	home	19912	0
African Men 8	Transcript	06/09/2011 12:08	1	0	home	21794	0
African Women 19	Transcript	06/09/2011 12:13	2	0	home	28398	0
African Women 5	Transcript	06/09/2011 12:12	1	0	home	19955	0
African Women 4	Transcript	06/09/2011 12:12	1	0	home	15448	0
African Women 3	Transcript	06/09/2011 12:12	0	0	home	26878	0
Caribbean Men 20	Transcript	06/09/2011 12:07	3	0	home	11808	1
Caribbean Men 14	Transcript	06/09/2011 12:06	1	0	home	24052	0
Caribbean Men 9	Transcript	06/09/2011 12:06	1	0	home	21876	0
Caribbean Women 30	transcript	06/09/2011 12:11	8	0	home	12690	0
Caribbean Women 28	Transcript	06/09/2011 12:11	4	0	home	14051	0
Caribbean Women 25	Transcript	06/09/2011 12:10	12	0	home	19962	0
Caribbean Women 18	Transcript	06/09/2011 12:10	6	0	home	14329	0
African Men 27	Transcript	06/09/2011 12:09	3	1	home	17683	0
African Men 24	Transcript	06/09/2011 12:09	1	1	home	17114	0

African Men	Transcript 23	06/09/2011 12:09	1	1	home	11365	0
African Women	Transcript 16	06/09/2011 12:12	5	1	home	24099	0
African Women	Transcript 7	06/09/2011 12:12	2	1	home	17474	0
Caribbean Men	Transcript 17	06/09/2011 12:07	9	1	home	18127	0
Caribbean Men	Transcript 10	06/09/2011 12:07	12	1	home	14190	0
Caribbean Men	transcript1	06/09/2011 12:07	4	1	home	23382	0
Caribbean Women	Transcript 26	06/09/2011 12:11	1	1	home	17957	0
African Men	Transcript 6	06/09/2011 12:08	2	2	home	23824	0
African Women	Transcript 11	06/09/2011 12:12	5	2	home	52936	0
Caribbean Men	Transcript 21	06/09/2011 12:08	8	2	home	23408	0
African Women	transcript2	06/09/2011 12:11	3	3	home	22449	0
Caribbean Women	interview15	06/09/2011 12:10	21	3	home	41792	0
Caribbean Men	Transcript 22	06/09/2011 12:08	20	7	home	26607	0

Appendix 11b MAXqda2 Memos

Memos								
Textgroup	Text	Paragraph	Code	Text Set	Title	Author	Creation date	Memotext
African Men	Transcript 27	61			Memo 27	home	28/11/2011 20:24	THAT THE DISEASE IS ONLY FOR BLACK PEOPLE, ONLY AFRICAN PEOPLE
African Men	Transcript 24	40			african way	home	11/09/2011 09:06	reactions of Africans to hiv
African Men	Transcript 23	57			Memo 26	home	15/09/2011 22:00	
African Men	Transcript 6	4			african thing	home	11/09/2011 09:09	an african way that constitutes risk to HIV testing
African Men	Transcript 6	41			hiv risk	home	11/09/2011 09:11	african thing and hiv risk
African Women	Transcript 16	77			Memo 29	home	06/09/2012 09:40	part of Africanness
African Women	Transcript 11	40			AIDS as African Thing	home	11/09/2011 09:20	In the context of herbal treatment
African Women	Transcript 11	44			African way	home	11/09/2011 09:22	stigmatisin behaviour of rejection
African Women	Transcript 7	33			hiv as african thing	home	11/09/2011 09:19	Suspicions that she had hiv in Africa but healed by prayer
African Women	transcript2	119			African thing	home	11/09/2011 09:25	gossiping as an African attribute - impact on coming forward for diagnosis
African Women	transcript2	20			African way	home	11/09/2011 09:27	Dishonesty in Africa - risk/impact on help seeking
African Women	transcript2	56			African way	home	11/09/2011 09:28	Rejection, stigmatisation and how it affects uptake of hiv care
Caribbean Men	Transcript 22	4			risk	home	06/09/2011 12:30	ignorance of preventative behaviour such as pep. pessimism about risk
Caribbean Men	Transcript 22	58			Lack of awareness of universal precautions by health personnel	home	06/09/2011 12:48	
Caribbean	Transcript	58			confidentiality	home	06/09/2011	Complexities of confidentiality.

Men	22						12:52	Who should know about a patient's diagnosis?
Caribbean Men	Transcript 22	78			maintaining normality	home	06/09/2011 13:02	attempts to avoid stigma by keeping silent. this could be a potential barrier to help seeking
Caribbean Men	Transcript 22	95			normality	home	06/09/2011 13:08	cautiousness when walking in the hospital, awareness of colour of HIV drug bags and caution storing HIV medication at home to pretend to be normal
Caribbean Men	Transcript 22	58			barriers to access	home	06/09/2011 23:44	This attitude can be a potential barrier to access meaning that people will not seek help when in need
Caribbean Men	Transcript 22	70			barriers	home	07/09/2011 00:07	fear of stigma and the resulting outcome - death as perceived is a barrier to help seeking
Caribbean Men	Transcript 17	59			HIV as an African thing	home	11/09/2011 08:52	in the context of health/risk behaviour - unprotected sex with African women is 'risk'
Caribbean Men	Transcript 21	52			access to health services	home	06/09/2011 14:57	staff attitude determines attitudes of service users to health services.
Caribbean Men	Transcript 21	54			access to health services	home	06/09/2011 15:00	standards of living affects access to health services. Focus in finding money than looking after health
Caribbean Men	Transcript 10	69			African thing	home	11/09/2011 09:00	African thing because many Africans die of it and so many are found at the clinic
Caribbean Men	transcript1	107			hiv as African thing	home	11/09/2011 09:03	many people in Africa suffering with hiv but have no treatment
Caribbean Women	Transcript 26	80			HIV as afrian illness	home	11/09/2011 09:17	so much hiv in Africa resulting in many deaths
Caribbean Women	interview15	28			African thing	home	11/09/2011 09:15	contesting hiv as an African thing
Caribbean Women	interview15	24			Memo 30	home	06/09/2012 14:27	Issues of disclosure
Caribbean Women	interview15	28			Memo 31	home	06/09/2012 14:37	

Appendix 11c: MAXqda2 coded segment

Coded segments									
Comment	Text	Code	Begin	End	Weight score	Segment	Author	Creation Date	Textgroup
	Transcript 22	other therapy	105	105	0	y destiny? Not hand it over as such for I believe I'm, I'm master of my own destiny. I have the power to affect my own life in a positive way. I have come to Buddhism only in the last few months and it's been very beneficial to me though definitely. Even though I'm late for the clinic today I had to stop to chant before i left because I knew it was more important to be late than to miss chanting opportunity. It is very important to me. If i don't do that every day that day might not go as well as i hope. It is very, very important to me.	home	07/09/2011 00:19	
	Transcript 22	fear of stigma	95	95	0	then I have to meet new people and identify myself as HIV positive person, when I try, when I pick them up, somebody else is going to be judging me, that is not perfect and being afraid of what would happen if meet somebody again as I said this is my local hospital and I can meet somebody else in pharmacy waiting although they give medications in bags. They gave me the first one in a brown bag with HIV medication in it (laughs) but when somebody is picking up a brown bag, a brown paper bag from pharmacy, you know, that was also a bit worrying.	home	07/09/2011 00:18	
	Transcript 22	perception of hiv	95	95	0	(laughs) but it doesn't seem like that and even though i take medication for other things every day; I am a diabetic so I take medication for that everyday but it still doesn't seem the same as taking HIV medication. Ok but if i don't take my HIV medication every day, it will become more complicated (laughs), although you know, that	home	07/09/2011 00:17	
	Transcript 22	fear of stigma	78	79	0	I think my opinion has changed in the few years that I have been diagnosed and the whole public and my experience is not easy. Every time they see your face when you are walking into the GUM clinic; every time I come here I am thinking, what if I meet someone I know and they ask me why are you going to the GUM clinic, I	home	07/09/2011 00:13	

						know that is something I have to overcome every time I walk through the corridor. That doesn't make it easier.			
	Transcript 22	perception of hiv/aids	78	78	0	Er.....what do I think.....er, not sure because I have to look at my own experience back. I thought it was a death sentence. However, my opinion has changed now. When I speak to friends who are not positive now, they are aware of the dangers around HIV and they test regularly and that is something I wasn't doing but then I didn't have reason for that because I was having safe sex at all, at all times and it was when I did not have safe sex, that I thought I was exposed and I realised what I had done immediately.	home	07/09/2011 00:11	
	Transcript 22	barrier to help seeking	70	70	0	Because they are afraid of what that means for them with regards to 'a dead sentence' and, and also being a part of that er.. a group of individuals who are positive which is not a pleasant thing to be proud of, the stigma that comes with that. I couldn't be as comfortable in the way that I socialise with other people. I am aware that any encounter, sexually, any sexual encounter could lead to disclosure for the other individual so that was something I was very afraid of so I had to alter my behaviour as such so i think that is a situation where people have to be aware of their behaviour and change or be aware of their own mortality other than that they are not confident that you know, live happily over my normal life span.	home	07/09/2011 00:07	
	Transcript 22	response to symptoms	67	67	0	I did the test but the only reason why I did the test was because I could see that I was physically suffering in some way but if I thought that I was exposed and I was not having any symptoms, maybe I wouldn't have got tested anyway. My education was not as good as I thought it was. I didn't realise the benefits of starting treatment early until I got diagnosed and came here.	home	07/09/2011 00:04	
	Transcript 22	staff attitude	67	67	0	or example I don't know what it is like today, if I came through the door; if I would have a similar experience like the one I had before; the lack of explanation. I don't think anything was done maliciously. I think when people do it day in day out, they become oblivious to the emotions of the individual so, had somebody treated me in a more gentle fashion and shown me what the future coming here was going to be like, in a gentler way with more understanding and explanation, then I would have found it easier; so in telling people, I would explain to them what to expect, though it is not all going to be easy. Most of it is going to be unpleasant and uncomfortable, to know that a lot of the conversation is going to be unpleasant and uncomfortable. However my attitude before diagnosis was; if I was HIV positive, I	home	07/09/2011 00:01	

						wouldn't bother to know. When I have to find out, then, fine, I would take medication.			
	Transcript 22	break of confidentiality	60	60	0	While they use numbers when communicating with you, on file is your name and that name went back to another clinic in this hospital and as a result of that, when the doctor then referred back to my GP on what I was having for my stomach complaint wrote there that I am HIV known. I never told my GP that; and my GP then contacted me and arranged a meeting. At the meeting he told me 'I have been made aware from the hospital, NPH, that following your stomach exams, you are HIV positive'. That was another conversation I did not expect to have with my GP and again it all came through this clinic as a result of me giving my name to this clinic and you know, for some reasons other than the jobs I do for example if people apply for work or mortgages, they ask me about my medical history and they may say, 'can we write to your GP?'. Now they will always have that information available as the GP cannot ignore it. It is on my file. That means that I was now exposed to having problems with the insurance, mortgage applications, with all types of things, job applications.....	home	06/09/2011 23:46	
	Transcript 22	risk awareness	40	40	0	Well everybody that I know that I have spoken to is aware of the dangers and the risks so there is no other thing I need to tell them other than discuss it. We are all aware that you can be er careful and expose yourself and not even the infrequency of it or just the one time or anything like that. That's that the only thing will be the danger of having unprotected sex with someone and then putting them at risk	home	06/09/2011 22:42	
	Transcript 21	access to health services	54	54	0	I fell ill, i fell ill! I couldn't get out of bed so, so that is the final stop because what am i going to do; i fell ill you see. The thing is that the living that black people are living here is more tougher, more tougher, rents, the living in, lifestyle has changed and become more tougher. Now people don't want no more to share anything so that is the only problem.	home	06/09/2011 14:59	
	Transcript 10	access to health services	69	69	0	African thing	home	06/09/2011 17:44	
African thing and impact on appropriate health behaviour	Transcript 17	access to health services	59	59	0	African thing	home	06/09/2011 17:44	
	Transcript 21	response to symptoms	28	29	0	They have actually improved my life rapidly because before I came in here it was worse than I thought it could be. I nearly fell down when I was at work the last day. When I went to work I made a silly mistake. I wasn't supposed to go in but I went in. I was in the toilet	home	06/09/2011 14:53	

						and I was dizzy. I nearly fell down because I was feeling some pain so my brain is not even working properly so I was not secure myself enough on the wall so I fell. I don't know how the whole thing is going to unwrap before I fall because I was managing to gain my health, deprived from sleep for I was waiting for 2o'clock midnight to wake up. My body was not agreeing. It wasn't going away because I wanted to get up and go to the toilet but I couldn't so by 4'oclock, i phoned the ambulance. I said i need help from them to go to the hospital.			
	Transcript 21	symptoms	4	4	0	leep and pain. I was feeling pains and started to take more and more pain killers and I moved on to nurofen, a more stronger one and started to take and still all my body is paining and I thought this is getting more serious. I had pain on my leg and on my back and when I rubbed it with some medication, there was pus there	home	06/09/2011 14:40	
	Transcript 22	lack of information	52	52	0	Well for me, I was very much unprepared for the whole process of coming to this clinic on a regular basis. So my advice would be that staff here should be aware that people coming through the door don't do this every day; though you may do it every day; so i got the impression that, erm, that some of the people here had forgotten that and they were talking to you as if you knew everything about everything which I didn't so a lot of things were coming in through one ear and going out through the other ear. And I also was very, very concerned with the sensitivity or lack of sensitivity that was around it; talking about my personal life such as infection and subsequent meetings that I would come back and they would ask me; 'have you had sex?', who with?, were you active or passive?, what role did you play and all that sort of questioning around my sex life. I wasn't expecting that, and I found that very difficult to be questioned in that way which no one had told me about during our earlier encounter and really I wasn't that and everything that happened was a surprise to me. When I think of the first day I entered here or maybe the first day I was confirmed as HIV positive, I would have liked to have it properly explained to me, what was going to be the way forward, the sort of meetings that I would have subsequently and what they involved rather sitting there and having these type of questions being thrown at me which I found very, very difficult to answer. They were very, very personal and it felt to me as though, at the time it felt to me like it was another punishment for being positive; that you lose yourself respect and you are treated in a disregarding	home	06/09/2011 13:28	

	Transcript 22	staff attitude	48	49	0	<p>– They, they...no, it wasn't very much a repeat as finding out what my status was with regards to my infection, viral load etcetera and CD4 count, so it was taken for granted that I was positive just because I said I was positive, that I had had a positive result but I was still hopeful at that time that I got it wrong so it was a little bit disturbing the fact that everyone here took it for granted that I had already come to terms with myself and then I was totally unaware of the subsequent meetings here, the intimacy of the questioning that I would have. That was very, very upsetting.</p>	home	06/09/2011 13:25	
	Transcript 22	reactions to diagnosis	44	45	0	<p>How I took the diagnosis..... Well, to begin with, it was ok, but over time, I think it became more upsetting. As I said because, I realised at the time I had exposed myself, I did not know about pep. When i was waiting for the symptoms I did not need anyone to tell me what they were. Of course I knew what the symptoms were so it was just confirmation that I'd got what I had thought. So I went to a private clinic to get the test done and it was confirmed. I was surprised that problems came afterwards after coming to this clinic here. Here I was very shocked at the err...almost laissez – faire attitude of people in the clinic here. It was deeply upsetting. I got the impression that erm I should be or they expected I was totally comfortable with my diagnosis so I was not told. Although I had been confirmed at the private clinic, I was still hoping that when I came here a few days later, that they would tell me that there was a mistake. However I was told in a very matter of fact way what the treatment would be etcetera, etcetera. There was no time taken to even talk about whether I was or wasn't positive.</p>	home	06/09/2011 13:24	
	Transcript 22	ignorance	18	19	0	<p>I knew immediately that I was exposed er and but I just thought there is nothing I can do now but wait so I was going to wait 3months and be tested but then the symptoms came prior to the 3months so I was already aware that it was probably symptoms of night sweating every night.</p>	home	06/09/2011 13:20	
	Transcript 22	BLUE	95	95	0	<p>then I have to meet new people and identify myself as HIV positive person, when I try, when I pick them up, somebody else is going to be judging me, that is not perfect and being afraid of what would happen if meet somebody again as I said this is my local hospital and I can meet somebody else in pharmacy waiting although they give medications in bags. They gave me the first one in a brown bag with HIV medication in it (laughs) but when somebody is picking up a brown bag, a brown paper bag from pharmacy, you know, that was also a bit</p>	home	07/09/2011 00:18	

						worrying.			
the need to understand the relationship between safe sex and hiv	Transcript 17	BLUE	59	59	0	Yeh they worry about it but I have witnessed, not actually witness, I have seen, I've seen friends, but I've seen friends who have practiced unprotected sex but at the same time they fear hiv	home	11/09/2011 08:50	
	interview15	BLUE	28	28	0	but the proportion of what they're saying in Africa, ninety odd percent that's rubbish, that's a lie, the only way that can happen is that you're, you're	home	11/09/2011 09:16	
	Transcript 7	BLUE	31	31	0	- No. I was not sick, only the pneumonia.. I had god fire on my side too and it all dry up but they did not say that I have HIV in Africa. It was something spiritual and my church was also praying for me and I got well.	home	11/09/2011 09:19	
	Transcript 11	BLUE	40	40	0	We've got AIDS in Africa; there would be herbs that probably do not have side effects that could be used. I would research this first before seeking medical treatment.	home	11/09/2011 09:20	
	Transcript 11	BLUE	44	44	0	if I was in Africa the reception I get even the reception it won't be shaking, they won't even touch the card maybe....laughs so look come on I'm thankful erm	home	11/09/2011 09:22	
	transcript2	BLUE	119	119	0	I don't move about, you know; the society here, the African society here are also there to talk about people, you know the African way so I don't worry to mingle with them so much so that's all. I keep to myself. And it depends. It's me really, that's what I think. Step by step, maybe in two years I might go home.	home	11/09/2011 09:25	
	transcript2	BLUE	20	20	0	Because they were here when he fell ill, So they just came to see him on his death bed and then, he had thrombosis in the beginning and we just created a story and when they ask this, what their father died of and, in Africa, everything is possible. They ask for a death certificate and it was issued with another type of.... (illness) hmm. We knew but we let it to be that way.	home	11/09/2011 09:27	
	transcript2	BLUE	56	56	0	But in Africa they will throw me out, they will hate me they will ostracise, me, they will segregate me, all that sort of thing and it... is still there, it will never stop.	home	11/09/2011 09:28	
	interview15	BLUE	24	24	0	What I'm capable of doing, I have to step back because I feel I'm not ready to tell people but that is the sad part of it and our people black people oh Lord, you only have to say one thing and they go wild.	home	06/09/2012 14:27	
	interview15	BLUE	28	28	0	creating that drug, and you're literally putting it in food if we stop taking all these milk powders and go back to the natural way of breast feeding, go back to our natural herbal remedy, I think we can't go wrong, we cannot go wrong. I talk too much	home	06/09/2012 14:39	

	interview15	BLUE	30	30	0	But this is how I feel, we need to, the media is not for us, it's not for black people because we are not going to get anywhere. They're not interested; they're not interested in our health. We have to make it known. In places where you've got erm, there's a centre at um, ooh, as you come away from the hospital you're going towards Harlesden, where they've got the cancer place for Afro-Caribbeans and other ethnic groups, put the signs in there, even put it around the doors	home	06/09/2012 14:40	
	Transcript 18	BLUE	79	79	0	Yes I have learnt a lot. They gave me leaflets and I have read all of them, I have also gone to the internet. That was the first time I went to the internet to look for information. That is the bad thing about it that if people haven't got it they will not go into the internet to look for information. When I read about it I got what I need to do. There are many information leaflets in here on the shelves and anyone can take it.	home	06/09/2012 15:33	
	transcript 30	BLUE	58	58	0	I have had lots of information. The nurse give me some leaflets, some papers and the health adviser talk to me about my medication, things like side effect. She say some can give cancer. She talk about the different regime, she talk about sex; she cover everything.	home	06/09/2012 19:13	
	Transcript 22	MAGENTA	44	44	0	How I took the diagnosis..... Well, to begin with, it was ok, but over time, I think it became more upsetting. As I said because, I realised at the time I had exposed myself, I did not know about pep. When i was waiting for the symptoms I did not need anyone to tell me what they were. Of course I knew what the symptoms were so it was just confirmation that I'd got what I had thought. So I went to a private clinic to get the test done and it was confirmed. I was surprised that problems came afterwards after coming to this clinic here. Here I was very shocked at the err...almost laissez – faire attitude of people in the clinic here. It was deeply upsetting. I got the impression that erm I should be or they expected I was totally comfortable with my diagnosis so I was not told. Although I had been confirmed at the private clinic, I was still hoping that when I came here a few days later, that they would tell me that there was a mistake. However I was told in a very matter of fact way what the treatment would be etcetera, etcetera. There was no time taken to even talk about whether I was or wasn't positive.	home	06/09/2011 22:46	
	Transcript 22	MAGENTA	58	58	0	I assumed wrongly that when you come here and fill out that first form, that information was specific for this clinic so I wasn't expecting that. I came for an appointment and was told, 'we just found out, can you wait?' So everybody was seen before me. I didn't	home	06/09/2011 23:36	

						understand that because I thought everybody was treated equally regardless of their status. With all the medical reasons, that is the reason why hygienic practices are put in place so there would be no reason for me to express my status to my doctor so in the end, that was a regret and I still regret it today that my name is on file because I don't trust that information to be held here at all. If I could change it I would. If I could advise anybody			
	interview15	MAGENTA	33	33	0	That is why as I was saying so many black men they die of cancer of the testicle because, they won't go, they think it's a shame and I've been pestering my husband for years and years, for over twenty odd years, go to the well men clinic. Yes I'll go, go, I'll come with you, yes I'll go oh I'm not going to go; the other day he, erm if he doesn't go to the toilet often and he gets constipated, and he's forced to go to the toilet then he gets problems, and I say well just go and show the doctor to have a look, he say 'have a look' and I say no, no I'm not looking at your backside, I said you know the doctors, they're for that. Not that I don't want to but I'm trying to encourage him. I say I'm not a doctor, what, okay, fine what's that going to show, I said you go to the doctor and explain, he goes to the doctor and he say to the doctor ok erm, I need erm some suppositories, because I'm constipated when I force myself in the toilet and it's hurting, then when he came back and he told me what he did and I said see there you go, I said my mother always said pride never feels pain, forget your pride, if your health is at risk go, if I have a pain I'm going. I said to him, look w	home	06/09/2012 14:45	
	interview15	MAGENTA	35	35	0	There's no embarrassment checking out your body. There's no embarrassment in the truth.	home	06/09/2012 14:47	
	interview15	MAGENTA	38	38	0	very professional, very good, great experience, yeah, friendly. The only, if I have to say anything, sometimes I wait a little bit too long but that's natural, because obviously they did explain and they do explain well somebody else who's just been diagnosed and they're going through problems, so therefore sometimes your wait might be a little bit longer but that's it, but see...	home	06/09/2012 14:53	
	interview15	MAGENTA	56	56	0	People, generally they look at HIV the same, same as AIDS. They don't seem to know the difference	home	06/09/2012 15:02	
	interview15	MAGENTA	56	56	0	I think at that particular time generally you know like when HIV first came out when someone died of AIDS, they bury them in a coffin and they seal the coffin. It was like a plaque, the 10 plaque of of the Egyptians, you know with the Egypt...you know when god gave to the Egyptians so it er.. people generalise, still generalise	home	06/09/2012 15:06	

						it like that,			
	Transcript 18	MAGENTA	62	62	0	I don't know how to reach old people....., some really want to but the effect of walking in the clinic, just coming to the clinic, some really want to be tested but but I think coming to the clinic here needs some amount of courage. If maybe if the clinic was treating other things, people can feel free to come but because it is isolated, it is something else. When you are coming here, once you get on the lift and press no 2, if there is anyone on the lift they start looking at you because they think you are coming here especially when you are a black person. If there are other wards here people will not know but because there is only, I think only one other clinic at no. 2, everyone seeing you here, the first thing that come to their head, this one has AIDS(home	06/09/2012 15:21	
	transcript 30	MAGENTA	38	38	0	I know about traditional medicine but i can't have it here, i mean i can't have it in this country. I haven't been back to Jamaica since 2 and half years now. If I go back to Jamaica, i may try it because, i know there are some bush in Jamaica, they use it for skin condition but i have not been dere [there]. Some use it to bath with, some you eat and some you put on the skin.	home	06/09/2012 19:07	
	Transcript 22	RED	48	48	0	They, they....no, it wasn't very much a repeat as finding out what my status was with regards to my infection, viral load etcetera and CD4 count, so it was taken for granted that I was positive just because I said I was positive, that I had had a positive result but I was still hopeful at that time that I got it wrong so it was a little bit disturbing the fact that everyone here took it for granted that I had already come to terms with myself and then I was totally unaware of the subsequent meetings here, the intimacy of the questioning that I would have. That was very, very upsetting.	home	06/09/2011 23:05	
ignorance and lay understanding of hiv spread	Transcript 17	RED	59	59	0	They think if i'm gonna make love or have sex with an African lady, I am gong to use a condom but I have heard women; also say if I have to have sex with an African man I will use condom but it seems like they wouldn't use a condom if it is somebody else because they think hiv comes just from African people though it has to do with pure ignorance.	home	11/09/2011 08:51	
	Transcript 17	RED	59	59	0	mixed messages ya, but here it is amazing the ignorance and the inexperience yes. T	home	11/09/2011 08:52	
justification of why hiv is an African thing	Transcript 10	RED	69	69	0	I also think that it is an African, an African thing because you have many Africans who suffer from it. You always have many of them in the clinic here and they also say many people die in Africa of HIV/AIDS. I	home	11/09/2011 09:00	

						think it is an African thing because almost everybody have it. I think some go to other hospitals too.			
	transcript1	RED	107	107	0	d cannot afford it, I mean you've got the chance to get it free and get the best and it's the best.	home	11/09/2011 09:02	
	transcript1	RED	107	107	0	Its like in Africa I mean when there are people there who cannot afford it you know; sometimes it hurts, it really hurts to know that sometimes your own black brother or black sister dying and they cannot be reached but the real thing is pain, it hurt deeply in, the thing, I wish this HAIDS or the treatment for HAIDS could spread among the unreachable people who really, really, really (need it) need it. And I wish everybody could just put his hand on the heart...and just.....	home	11/09/2011 09:03	
African way impacting on help seeking	Transcript 24	RED	40	40	0	The minute you tell one person, the next minute the community will all be looking at you. If I tell especially an African here, the next minute all the Africans will know like in Africa and you will have no friend. And the family will not want to come near you, you know what I mean, they will keep their distance. So for me to be happy i'll, i er.. have to keep it to myself	home	11/09/2011 09:05	
	Transcript 6	RED	4	4	0	Those things they do bribing people. That is African things not over here but they bring it over here, doing those things but you know that you are infected with HIV . We must protect the innocent people; don't just go killing people and showing them fake papers like you're not infected with HIV positive, somebody will believe you or you are killing the innocent.	home	11/09/2011 09:09	
	Transcript 6	RED	41	41	0	This thing they do in Africa, Africa people know that they have the HIV, but they keep quiet to infect other people, that's what she's doing here.	home	11/09/2011 09:11	
	Transcript 26	RED	80	80	0	First when I was diagnosed, I thought I was going to die within a few months but here I am still alive. I used to think that when you get it you die and I hear that many people are dying in Africa	home	11/09/2011 09:17	
	Transcript 27	RED	20	20	0	African er heritage	home	28/11/2011 20:18	
	Transcript 27	RED	26	26	0	knowing people the way I have known er our Africans, i wou	home	28/11/2011 20:19	
	Transcript 27	RED	61	61	0	and the general perception is that the disease is for black people; Africans, no, no, no, it's just for black people is the perception that they have got.	home	28/11/2011 20:24	
	Transcript 23	RED	65	65	0	hey call it black people sick. I don't trust them. They take it to Africa and they say Africa people have HIV. I tell you,	home	28/11/2011 20:31	

	Transcript 8	RED	88	88	0	like Africa, you have to	home	28/11/2011 20:46	
	Transcript 19	RED	30	30	0	know that Africans; er.	home	28/11/2011 20:53	
	Transcript 19	RED	36	36	0	you know what Africans are like so, when an African person is speaking	home	28/11/2011 20:54	
	Transcript 16	RED	51	51	0	because in Africa when they say people have HIV, people thinking tomorrow you will die	home	28/11/2011 20:59	
	Transcript 16	RED	77	77	0	In Africa we don't have support that's why we die an	home	28/11/2011 21:00	
	Transcript 16	RED	92	92	0	don't understand but for Africa you can understand because we've got double life	home	28/11/2011 21:02	
	Transcript 11	RED	21	21	0	This is just a typical African reaction	home	28/11/2011 21:12	
	Transcript 11	RED	26	26	0	but only if Africans will remove the element of judgment	home	28/11/2011 21:13	
	Transcript 11	RED	30	30	0	this is where, typical African reaction,	home	28/11/2011 21:13	
	Transcript 7	RED	61	61	0	I see many African people	home	28/11/2011 21:16	
	Transcript 5	RED	55	55	0	typical African!.	home	28/11/2011 21:17	
	Transcript 4	RED	55	55	0	I see here are blacks, African people	home	28/11/2011 21:22	
	interview15	RED	32	32	0	when I look at this clinic, at first when I used to come here, I'm thinking oh my lord, look at, look at it, you know you come up the stairs every body knows where you're going to, when you're pressing the buzzer to the second floor, they're thinking, you're either going to visit someone, you're either going to erm the sickle cell section or you're going to the, you're going to the erm HIV clinic or sexually transmitted disease clinic but straight away, my mind works every time, and when I come up those stairs, even now when I'm coming and I see loads of people, I'm thinking lord, I just hold my head up high, and I'm thinking, I'm not looking left, I'm not looking right I'm not looking centre, so imagine me at my age, you know, which is a dreadful shame,	home	06/09/2011 14:42	
	interview15	RED	58	58	0	They need lessons on that so they don't think or you've got HIV because I, I even though I did the course and everything years back, erm you know, when I found out I literally in a minute thought it's going to develop into AIDS and I'm going to die. That's why I asked the doctor 'how long have I got to live?' and he looked at me as if I was crazy but er I came back and I started	home	06/09/2011 15:10	

						researching, I started reading up on it			
	Transcript 25	RED	32	32	0	Well I asked the consultant if I've got HIV or AIDS and he said to me, 'no you've just got the virus, you haven't got AIDS' and he explained to me but I've never had er.. the thing is that people get confused between HIV and AIDS. The consultant explained the difference to me.	home	06/09/2011 15:46	
	Transcript 25	RED	56	56	0	I thought I was doing the right thing but I was shocked by their reaction. They suspended me and dismissed me later after the investigation.	home	06/09/2012 115:50	
	Transcript 25	RED	73	73	0	I mean when I come here, the more people I seem to see are Africans. I don't see many Jamaicans here.	home	06/09/2011 15:56	
	Transcript 22	GREEN	105	105	0	y destiny? Not hand it over as such for I believe I'm, I'm master of my own destiny. I have the power to affect my own life in a positive way. I have come to Buddhism only in the last few months and it's been very beneficial to me though definitely. Even though I'm late for the clinic today I had to stop to chant before i left because I knew it was more important to be late than to miss chanting opportunity. It is very important to me. If i don't do that every day that day might not go as well as i hope. It is very, very important to me.	home	07/09/2011 00:19	
African thing	Transcript 17	GREEN	59	59	0	They think it's just from African people it comes from, an African thing, and I know	home	11/09/2011 08:49	
use of complementary and alternative med	Transcript 16	GREEN	71	71	0	oh you know I am born in the village and I always use the traditional treatments. I can't lie to you because sometime I am not taking the medicine to the doctor because she right but she can't understand what is happened but I, I've got some traditional medicine who make me strong because sometime I am tired and when I am tired like this I drink and I sleep aloo.. When I get up I can do everything I want. If somebody just said this, I can try. I can't lie to you I can try and it is fine. I've got some who make me strong, why not?	home	06/09/2011 09:38	
lay beliefs/conspiracy theories	interview15	GREEN	28	28	0	There are so many herbalist, so many things we can take, what where are they putting it in. I remember in my country there were times when they didn't urn, they didn't give the children the measles injection because they found that they actually put virus in the measles injection to send it abroad. Sometimes they can do these things and make it into powdered form; they put it into the milk. People should be aware of all these things because these are the type of things that they do. They send you batches, that batch they know where this is going, that is going and that and now in my country with the research they do not really buy meat or stuff from urn England goes to other channels because they cannot	home	06/09/2011 14:36	

						trust what they're actually giving you			
	interview15	GREEN	28	28	0	They use that meat only for one thing – destruction so I go to, if I go in there and I see their own people buying the meat, I'll go and buy. If I go to the shop, an English shop, meat shop, the butchers and I see only my black people in there, I will not go in there to buy but where I see their people are buying then I know, oh well if you are getting it for yourself then the meat is good (laughs) so I also go and buy.	home	06/09/2011 14:37	
	Transcript 18	GREEN	76	76	0	Nowadays some people understand more about it, some are ignorant about it and some don't even know about it. Someignorant people who don't know about it and some really understand about it. There are some who just stand up and go to people and say I've got it, I have got it... There are some who still believe that they can have it by sharing a cup or a spoon...I think a lot of people do not still understand what it is all about. Or that reason there is a lot of negative attitude against people who are positive even in their families.	home	06/09/2011 15:30	
	Transcript 25	GREEN	12	12	0	No, not counselling as such but they spoke to me about the medication, about what to expect ..er... well maybe I should say yes because they explained to me what the procedure was and what will be happening. I spoke to a couple of people and that time, to me it was not like serious counselling. It was afterwards when i start my treatment that I was talking to the nurse specialist who was guiding me and that sort of a thing, telling me how I can manage myself with the illness.	home	06/09/2011 15:38	
	Transcript 25	GREEN	38	38	0	hope it does work! I mean somethings do work. I know back in my country, we've got like different bushes that they say will work for colds and stuff and they do work so if there was something, yeh! It will help me stop taking these tablets. Ya! I would if it works. If there was research that it worked, I will definitely take it, yes.	home	06/09/2011 15:48	
	Transcript 25	GREEN	77	77	0	I've got loads. I think I've got enough of what I need to know added to the information that I had before as I said. It is not something that I pay attention to a lot. There is lots of papers here with information and I have read most of them. I pick all the leaflets I want. I use the internet a lot more and i know a lot more about HIV now.	home	06/09/2011 15:57	
	Transcript 28	GREEN	18	18	0	Well that I had HIV! That's it! Finish. It was like i was dead, then i met B..... and he said HIV no longer kills and that i can die from something else not HIV. Because it is just HIV, You don't have AIDS or whatever.....	home	06/09/2011 16:45	

	Transcript 28	GREEN	33	33	0	i used to hear that ahhh people that have AIDS and HIV they are people that just go around and around	home	06/09/2011 16:51	
	transcript 30	GREEN	42	42	0	Even they say stigma is there, only the people in this clinic know I have the sick, so nobody treat me like I have the sick out of here because they don't know i have it. People here, they don't do things that I feel stigma but when a man I like want a relationship, I say no, because I don't know how I will start say to him "please use condom, use condom. If he love me and want permanent relationship, he will want to know why me want him to use condom. It's bad, its bad if me lie and carry on lying. I do not want to infect anyone because I will live with it. I know someone infected me, knowingly or unknowingly. In this sense I feel stigma because I keanot [cannot] do them things that I want for do like any normal person., I want to keep my illness to myself.	home	06/09/2011 19:09	
	transcript 30	GREEN	46	46	0	It is not that black people think like that. Black people too proud, it's pride and shame that put them off. Sometimes it's fear because them don't know what for do if them have the illness. A black man is a black man. You cannot really convince them to go get them hiv test. Maybe when they start having some illness (symptoms) symptoms, yes they can go to have test but if the symptom not serious they don't want to go	home	06/09/2011 19:10	
lay beliefs/conspiracy theory	Transcript 16	ly beliefs	94	94	0	They was talking about HIV. There were doctors and traditional practitioners and this that and there was one man who called from one African country, he said er...we er..er black people is so stupid because like here they said they've got malaria tablets but there is no malaria here. How can I get malaria tablets? They always send us injection for the sickness we er.. They don't have here and he thinks they did something, some injection to send to us to get this thing because, he can't understand why they say this sickness, you can have it from sex, if you can have it from sex then everyone can have this sickness because the men, I am talking today, I have got 6 girlfriends. If I am	home	06/09/2011 09:47	
	interview15	conspiracy theory/lay beliefs	28	28	0	They use that meat only for one thing – destruction so I go to, if I go in there and I see their own people buying the meat, I'll go and buy. If I go to the shop, an English shop, meat shop, the butchers and I see only my black people in there, I will not go in there to buy but where I see their people are buying then I know, oh well if you are getting it for yourself then the meat is good (laughs) so I also go and buy.	home	06/09/2011 14:38	
	interview15	lay beiefs	30	30	0	But this is how I feel, we need to, the media is not for us, it's not for black people because we are not going to	home	06/09/2011 14:40	

						get anywhere. They're not interested; they're not interested in our health. We have to make it known. In places where you've got erm, there's a centre at um, ooh, as you come away from the hospital you're going towards Harlesden, where they've got the cancer place for Afro-Caribbeans and other ethnic groups, put the signs in there, even put it around the doors.			
	interview15	barrier to access	32	32	0	when I look at this clinic, at first when I used to come here, I'm thinking oh my lord, look at, look at it, you know you come up the stairs every body knows where you're going to, when you're pressing the buzzer to the second floor, they're thinking, you're either going to visit someone, you're either going to erm the sickle cell section or you're going to the, you're going to the erm HIV clinic or sexually transmitted disease clinic but straight away, my mind works every time, and when I come up those stairs, even now when I'm coming and I see loads of people, I'm thinking lord, I just hold my head up high, and I'm thinking, I'm not looking left, I'm not looking right I'm not looking centre, so imagine me at my age, you know, which is a dreadful shame,	home	06/09/2011 14:42	
	interview15	barriers to help seeking	33	33	0	That is why as I was saying so many black men they die of cancer of the testicle because, they won't go, they think it's a shame and I've been pestering my husband for years and years, for over twenty odd years, go to the well men clinic. Yes I'll go, go, I'll come with you, yes I'll go oh I'm not going to go; the other day he, erm if he doesn't go to the toilet often and he gets constipated, and he's forced to go to the toilet then he gets problems, and I say well just go and show the doctor to have a look, he say 'have a look' and I say no, no I'm not looking at your backside, I said you know the doctors, they're for that. Not that I don't want to but I'm trying to encourage him. I say I'm not a doctor, what, okay, fine what's that going to show, I said you go to the doctor and explain, he goes to the doctor and he say to the doctor ok erm, I need erm some suppositories, because I'm constipated when I force myself in the toilet and it's hurting, then when he came back and he told me what he did and I said see there you go, I said my mother always said pride never feels pain, forget your pride, if your health is at risk go, if I have a pain I'm going. I said to him, look w	home	06/09/2011 14:45	
	interview15	access	38	38	0	very professional, very good, great experience, yeah, friendly. The only, if I have to say anything, sometimes I wait a little bit too long but that's natural, because obviously they did explain and they do explain well somebody else who's just been diagnosed and they're	home	06/09/2011 14:53	

						going through problems, so therefore sometimes your wait might be a little bit longer but that's it, but see...			
	interview15	knowledge	56	56	0	People, generally they look at HIV the same, same as AIDS. They don't seem to know the difference	home	06/09/2011 15:02	
	interview15	barriers to access	56	56	0	I think at that particular time generally you know like when HIV first came out when someone died of AIDS, they bury them in a coffin and they seal the coffin. It was like a plaque, the 10 plaque of of the Egyptians, you know with the Egypt..you know when god gave to the Egyptians so it er.. people generalise, still generalise it like that,	home	06/09/2011 15:06	
	interview15	knowledge about HIV	58	58	0	They need lessons on that so they don't think or you've got HIV because I, even though I did the course and everything years back, erm you know, when I found out I literally in a minute thought it's going to develop into AIDS and I'm going to die. That's why I asked the doctor 'how long have I got to live?' and he looked at me as if I was crazy but er I came back and I started researching, I started reading up on it	home	06/09/2011 15:10	
	Transcript 18	Barrier to access	62	62	0	I don't know how to reach old people....., some really want to but the effect of walking in the clinic, just coming to the clinic, some really want to be tested but but I think coming to the clinic here needs some amount of courage. If maybe if the clinic was treating other things, people can feel free to come but because it is isolated, it is something else. When you are coming here, once you get on the lift and press no 2, if there is anyone on the lift they start looking at you because they think you are coming here especially when you are a black person. If there are other wards here people will not know but because there is only, I think only one other clinic at no. 2, everyone seeing you here, the first thing that come to their head, this one has AIDS(home	06/09/2011 15:21	
	Transcript 18	knowledge about HIV	76	76	0	Nowadays some people understand more about it, some are ignorant about it and some don't even know about it. Someignorant people who don't know about it and some really understand about it. There are some who just stand up and go to people and say I've got it, I have got it.. There are some who still believe that they can have it by sharing a cup or a spoon...I think a lot of people do not still understand what it is all about. Or that reason there is a lot of negative attitude against people who are positive even in their families.	home	06/09/2011 15:30	
	Transcript 18	Sources of information	79	79	0	Yes I have learnt a lot. They gave me leaflets and I have read all of them, I have also gone to the internet. That was the first time I went to the internet to look for information. That is the bad thing about it that if people	home	06/09/2011 15:33	

						haven't got it they will not go into the internet to look for information. When I read about it I got what I need to do. There are many information leaflets in here on the shelves and anyone can take it.			
	Transcript 25	information source	12	12	0	No, not counselling as such but they spoke to me about the medication, about what to expect ..er... well maybe I should say yes because they explained to me what the procedure was and what will be happening. I spoke to a couple of people and that time, to me it was not like serious counselling. It was afterwards when i start my treatment that I was talking to the nurse specialist who was guiding me and that sort of a thing, telling me how I can manage myself with the illness.	home	06/09/2011 15:39	
	Transcript 25	knowledge about HIV	32	32	0	Well I asked the consultant if I've got HIV or AIDS and he said to me, 'no you've just got the virus, you haven't got AIDS' and he explained to me but I've never had er.. the thing is that people get confused between HIV and AIDS. The consultant explained the difference to me.	home	06/09/2012 11:15:46	
	Transcript 25	Alternative med	38	38	0	hope it does work! I mean somethings do work. I know back in my country, we've got like different bushes that they say will work for colds and stuff and they do work so if there was something, yeh! It will help me stop taking these tablets. Ya! I would if it works. If there was research that it worked, I will definitely take it, yes.	home	06/09/2011 15:48	
	Transcript 25	perceptions of hiv	56	56	0	. I thought I was doing the right thing but I was shocked by their reaction. They suspended me and dismissed me later after the investigation.	home	06/09/2011 15:51	
	Transcript 25	african illness	73	73	0	I mean when I come here, the more people I seem to see are Africans. I don't see many Jamaicans here.	home	06/09/2011 15:57	
	Transcript 25	information source	77	77	0	I've got loads. I think I've got enough of what I need to know added to the information that I had before as I said. It is not something that I pay attention to a lot. There is lots of papers here with information and I have read most of them. I pick all the leaflets I want. I use the internet a lot more and i know a lot more about HIV now.	home	06/09/2011 15:58	
	Transcript 28	knowledge about hiv	18	18	0	Well that I had HIV! That's it! Finish. It was like i was dead, then i met B..... and he said HIV no longer kills and that i can die from something else not HIV. Because it is just HIV, You don't have AIDS or whatever.....	home	06/09/2011 16:46	
	Transcript 28	form of therapy	55	55	0	I really liked it i really liked it i really liked the massage, yes it was good but I just don't feel like doing it but it was so good to me my mind my soul, it was good I was pregnant, my partner said oh you gonna take off your clothes in front of somebody to get a massage laugh	home	06/09/2011 16:55	

	transcript 30	alternative med	38	38	0	about traditional medicine but i can't have it here, i mean i can't have it in this country. I haven't been back to Jamaica since 2 and half years now. If I go back to Jamaica, i may try it because, i know there are some bush in Jamaica, they use it for skin condition but i have not been dere [there]. Some use it to bath with, some you eat and some you put on the skin	home	06/09/2012 19:07	
	transcript 30	stigma	42	42	0	Even they say stigma is there, only the people in this clinic know I have the sick, so nobody treat me like I have the sick out of here because they don't know i have it. People here, they don't do things that I feel stigma but when a man I like want a relationship, I say no, because I don't know how I will start say to him 'please use condom, use condom. If he love me and want permanent relationship, he will want to know why me want him to use condom. It's bad, its bad if me lie and carry on lying. I do not want to infect anyone because I will live with it. I know someone infected me, knowingly or unknowingly. In this sense I feel stigma because I keanot [cannot] do them things that I want for do like any normal person., I want to keep my illness to myself.	home	06/09/2011 19:09	
	transcript 30	stigma	46	46	0	It is not that black people think like that. Black people too proud, it's pride and shame that put them off. Sometimes it's fear because them don't know what for do if them have the illness. A black man is a black man. You cannot really convince them to go get them hiv test. Maybe when they start having some illness (symptoms) symptoms, yes they can go to have test but if the symptom not serious they don't want to go	home	06/09/2011 19:10	
	transcript 30	information	58	58	0	I have had lots of information. The nurse give me some leaflets, some papers and the health adviser talk to me about my medication, things like side effect. She say some can give cancer. She talk about the different regime, she talk about sex; she cover everything.	home	06/09/2011 19:13	
	Transcript 22	information	54	55	0	It didn't make me feel better when I was asked those very personal questions (smiles sarcastically!) because I had no idea that, that was going to be part of my future. Yes, so I would have liked somebody to have told me on day one; I mean, here this is what is going on, this is what your experiences are gonna be like, this is the kind of information that we are going to need and this is why we need it but nobody did that.	home	06/09/2011 20:02	
	Transcript 9	barrier to help seeking	34	34	0	M – No, Well I think I was in what I call denial; which er.. Lots of people suffer from denial but er denial; 99.9% of people suffer from denial; even when they say they don't, they do. Somewhere along the line, people suffer from denial.	home	06/09/2011 21:40	

	Transcript 17	perceptions of health	10	10	0	- no because the boils were, at first, at first, in the first year, they came once, hardened once so I thought it was only the friction there or something and I remember the 2nd year, the site, well it came back two times for that year, 2, 3 times and then that is why I started getting really concerned because I said , 'what is this, what is this thing? And then the 3rd year, it started to come once every three months so by then I said to myself 'something is wrong, let me go and get checked out at the GUM clinic' just to make sure that nothing is seriously, is happening to my body. That is the only reason why.	home	06/09/2011 22:27	
	Transcript 17	information and communication	40	41	0	-ya, I have thought about this and why do a lot of black people not go for HIV test and I think to get them in to be checked er... I think, this is one of my ideas, maybe using er.. Somebody who will be the medium, somebody who will be respected , maybe a musician, a musician from the west indies, or africa or America and if there is a big campaign with this famous person on it, I am pretty sure a lot of black people will come forward and have a check especially if that person was diagnosed with it themselves and was brave enough to let the world know [like Magic Johnson...] ya like magic Johnson or..... any sort of likeer I know Carey west does it or well I don't know but i am pretty sure he has been for HIV positive..... But if somebody like him came out and have er..was doing publicity to show the black community that look go and get checked up for HIV It would help, it w	home	06/09/2011 22:58	
	Transcript 17	ignorance	43	43	0	they give you a cup of tea and when you are not seeing them, they throw away the cup because they they can't reuse it again you know; er you know, i have heard so many conversations about HIV in the past and like I said, I used to be one of those ignorant people and I have heard people say such and such has got HIV and they work in that restaurant and then no body goes there and people say oh such and such has got HIV and people say I am not gonna let my child go round there or I don't want my child around them so i have heard all these things	home	06/09/2011 23:01	
	Transcript 17	wys of raising awareness	51	51	0	Possibly er, erm, if if, probably if the gov't came up with a new load of ads that went on the tv, a load of new ads, a lot of forces put behind them, that, I think that will definitely make a lot of black people and enough people to come forward to have HIV test. I am pretty sure it's how they market it and how they put it across. It seems like at this present moment hiv seems not to be so important because you hardly hear a lot about it in the	home	06/09/2011 23:04	

						media. Er I remember back some time ago when the HIV and AIDS came out and I remember very clearly, there was adverts on the tv four times if not more every single day on every tv channel and some stock in my mind. And then went so its like don't see it on tv or don't hear about it on the radio, it's like its not in your mind. Its like sort of all about...so maybe if the government could push it more on the tv and in the media it would help people come forward to have the test.			
	transcript1	information needs	21	21	0	Does my body going to take the treatment well or does my body going to reject it? And if I take the treatment, does I going to get much sicker? Or my system turn, actually I don't know. So that is how, that is the first thing that come into my mind, nothing else doesn't worry me at all; the fact is that I have it, i have the sickness. I just want not to dealt not with the (past) past but to deal with the present and I try to as much as, I don't worry about whether I have the the, the virus, I don't worry. I just try to go out there, I try to go put myself in groups, try to learn about it more and advice although I know a lot of things about it so it's more.....this thing is very wide, so you doesn't,..... Everyday there is a different thing how they treat it so it is wide; so it doesn't have worry... I don't think that is the main thing, the worry...	home	06/09/2011 23:13	
	transcript1	knowledge about hiv	37	37	0	I think if I was doing the right way going, having safe sex, having sex with condom, this, then this wouldn't happen. When you don't use protection, you are likely to have any sickness, ...errm..., anything can be happen to you so you have to be erm.. careful,... my advice to people whether young, hold or what: always make certain that you have the condom, in everything that they do, have the condom.	home	06/09/2011 23:16	
	Transcript 14	perceptions of hiv	29	29	0	That's one of the things that I think needs to have like a parent focus where the parents need to know about infections where for example, they could be able to say that child has been diagnosed with this. It is not a dead sentence	home	07/09/2011 00:19	
	Transcript 21	symptom appraisal and reaction	4	4	0	I was not feeling well for some time. I tried to, tried to take some tablets but it was not really responding especially in the beginning, it was, last year; I had a problem with one of my teeth. It was painning me and sometimes it smells as well so I will go and buy some mouth wash or some strong liquid to wash my mouth with to deal with the problem but it did not go away. I'm the only one who knows the problem so this year I started getting tired. After sometime I begin to know that I am expecting to sleep. When I sleep for long I still get	home	07/09/2011 20:15	

						up and feel that I have not slept enough and only want to go back to sleep. That means if I sleep, I could sleep say for 6 hrs constantly but even if I sle			
	Transcript 21	self medication	6	6	0	That was mid ...er beginning of this year. That is when I saw the changes of my life. It was everything from 'running stomach', bad health and like i could i felt pains in my body but after June it is when I started to get worse. This is when i noticed that this is not ordinary as it had looked to me but I tried still to use the chemist and stuff so I went to the GP, I was, I had a rash on my chin so he prescribed some antibiotics to cure that one so I went away not knowing the problem is still there. When I came into the hospital after September, I then realised that CD4 count is very low, so low beyond, below 200 and my system is not just coping with anything anymore. So whatever I take, whatever I drink, it doesn't matter but now, it has improved, it has improved. The CD4 count has improved to more than 200 now and the viral load has reduced too. It was 9999 but now is, now it is 800 and something or so.	home	07/09/2011 20:16	
	Transcript 21	perceptions of health and illness	12	12	0	No, no, first I wasn't aware of what is going on. I was trying to fight my own battle. I was trying to secure what I can secure to go to work the next day. That was all my problem. My issue was, I wasn't thinking of anything else. I even recognise I am sick till, till the last two days before I came into hospital, when I realised no! This is not, all is not well.	home	07/09/2011 20:18	
	Transcript 21	knowledge about hiv transmission	36	36	0	I was, I was in fact, I was surprise to have the HIV in the first place. I was surprised because I was staying away from all sort of sex; I was minding my own business so I was very shocked. If I've got it, it could be by a mistake somewhere or maybe I have kissed somebody who has got that HIV, Who has caused that, that thing, but, but for the doctor to actually explain it to me properly, it means that I've got it in about 2 – 3 years back but I think my immune system was strong, fighting and fighting it until it was getting worse;	home	07/09/2011 20:24	
	Transcript 21	disruptions in biography	46	47	0	It has, it has, it has, the whole infrastructure has been changed, my thinking, my worries, everything has been changed. I have not even finalised how my life is going to run yet and I am no longer thinking of going because I wanted to move, I wanted to go home next year but this has changed. I have to wait and see how I get on; and getting a partner now because I don't want to come clean about it. I don't have to be clean with them and stay together with them, that's it period!	home	07/09/2011 20:29	
	Transcript 20	multiple	28	28	0	o me have them with 4 different womans them, me get 4	home	07/09/2011 21:10	

		relationships				of them with my first wife. That one, she leave me for another man. Other children, have different mothers too			
	Transcript 20	barriers to help seeking	68	68	0	Tell them you can live if this sick diagnose early. If you wait to fall sick your dead near, your dead near nurse. Me not on medication as yet. But the problem is black man too proud and the stigma too make them fear.	home	07/09/2011 21:43	
	Transcript 20	information sources	76	76	0	– Me, I receive plenty of counselling from that lady, What them call her again like that..erm, health adviser. Nurse them and them docta who see me when me come here give me plenty information about my sick and that tablet. Me not taking tablet yet. Them tell me how to stay healthy and many things. Them give me plenty of leaflet be can't read so much so me, I can't take the paper.	home	07/09/2011 21:44	
	Transcript 10	symptoms	6	6	0	I was having fever and cough. The cough stop and go and come back. My chest just full of stuff. Sometimes I have diarrhoea too. It will come on and go and come again. This one go on for a long time, like for 5 or 6 months.	home	07/09/2011 21:49	
	Transcript 10	self care	6	6	0	I will go and buy cough medicine from the chemist and the cough will go away today and come back and I sometimes I just have pain in my body and I have fever as well	home	07/09/2011 21:51	
	Transcript 10	self care	10	10	0	In the past I have taken cough syrup that I buy from the chemist and I sometimes too I but medicine for other thing like pains and when I have cold too and they have worked. This time this one did not do anything, it look like it did not work this time. I was like confused when this one did not work well.	home	07/09/2011 21:52	
	Transcript 10	response to symptoms	12	12	0	No, no, it was not so bad so I did not think of going to the GP just yet. I wanted to deal with it first so I kept thinking that I will get better. But I wasn't getting better; it was getting worse so I decided to come into hospital here by ambulance after which I was referred to this clinic. I didn't even know why until they say I had them sickness.	home	07/09/2011 21:53	
	Transcript 10	perception of hiv	36	36	0	I will advise them to test, to test, not to do self medication because the problem will not go away. The earlier you test and know your status the better for you. HIV is not AIDS so they should not be afraid to come for the test. Before, I used to think that HIV is the same as AIDS but when they diagnose me, they tell me HIV is when you have the virus and AIDS is when the virus has already attacked your immune system and your body don't have any defence for other sickness; that is when you have AIDS	home	07/09/2011 22:00	

	Transcript 10	disruptions in biography	46	47	0	To be honest with you, not anymore. You know what I am saying. I would have liked to have a family but not anymore. Having a family should be a simple natural process but I do not really want to get involved in any calculated activity, To be honest, I can't be bothered, it is too much hassle, yes i really think it is too much hassle, and all those sort of things.. Really i er....i don't want to go through all that, you understand what I'm saying? CA - But you can still have a	home	07/09/2011 22:03	
	Transcript 10	knowledge of HIV	42	44	0	I don't know much about any of those and I haven't tried them. As I said, HIV has no cure so I don't think any of this can be of any good. I would only try scientific medicine to be honest with you. Here they check your CD4 count and things like that and then, I think, I think this is helpful, yes because it lets them know what tablets to give you and they also change your medication if it is not working well or if you are having too many side effects. CA - Tell me how your diagnosis has changed or influenced any aspect of you. G-10910-CM -yes er, I think I see things now differently. I am more tolerant of everyone and I think I sort of value life more than i did before. I understand now that HIV can affect everybody. I also now understand that HIV is different from AIDS. I am more accommodating of people, of everyone and I try to live my life to the fullest. I am determined to get better.	home	07/09/2011 22:04	
	Transcript 10	barriers to access	54	54	0	am beginning to get used to it. When I was newly diagnosed it was very difficult for me especially coming to the clinic here. You know because this clinic is for the HIV patients, everybody know it. As soon as they see you coming this way it means you are HIV. So at first, before coming towards this direction I will look round to make sure that no one sees me coming in here, yes it is very difficult but I am beginning to get used to it. Since I started coming here I have not met anyone I know but it is ok if I meet someone I know in the clinic because then, it will mean that, he is also a patie	home	07/09/2011 22:06	
	Transcript 10	information about hiv	58	59	0	I think coming to the hospital is a personal thing. You cannot force people to come out and test. Immediately you bring that kind of topic people may think that you are judging them and some people might not be very happy about it. But I think you people as a hospital or as people who work with HIV can advertise it on newspaper or on the television. Everybody watches the television . If you talk there and tell people to come and test and why, I believe	home	07/09/2011 22:09	

						they will come.			
	Transcript 10	information	63	63	0	Oh yes I have received so much information. There is the health adviser who talk to me. When I was losing weight, the dietician talked to me. They give you lots of leaflets here like those ones that you have on the shelf behind you. Sometimes you cannot even read all of them. I don't keep them in the open in my house because I don't what anyone to see and start asking me what I am doing with them papers.	home	07/09/2011 22:13	