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**DISCLOSURE, CONCEALMENT AND EXPOSURE: HOW
BLACK IMMIGRANT MEN FROM EAST AFRICA LIVING IN
THE UK AND THEIR FAMILIES MANAGE
COMMUNICATION ABOUT HIV-POSITIVE STATUS**

JOHN OYANGE ACHWAL OWUOR

A thesis submitted to the University of Huddersfield in partial fulfilment
of the requirements for the degree of Doctor of Philosophy

The University of Huddersfield

May 2014

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ABSTRACT

Abstract

The aim of this study was to explore what it means for London-based, immigrant Black East-African men and their female partners to live with HIV. Few studies have been conducted on this issue with the present study population. The main thrust of existing research has been on preventing new infections, and work on living with HIV has mostly focused on groups in which the disease has a higher prevalence in developed societies, for example men who have sex with men. A modified grounded theory methodology underpinned by a symbolic interactionist theoretical framework was adopted. Data collection involved in-depth interviews with 23 participants, including: one HIV-negative man in a sero-discordant relationship; 11 HIV-positive men; six HIV-positive women, five of whom were partners of an HIV-positive research participant; and five workers from London-based community organisations offering HIV-related services accessed by Black Africans. Most (13/17) of the HIV-positive research participants opted to partially conceal their condition. In consequence, they faced an ongoing dilemma regarding whether to reveal their HIV-positive status to particular individuals. Disclosure could potentially unlock sources of social support, but also created the risk of stigmatization. But concealment meant forfeiting potential social support sources, and created risks of exposure. Four of the 18 research participants had eventually decided to 'come out' publicly in order to challenge stereotypes about HIV. They demonstrated that open communication about HIV-positive status can be a viable alternative to selective concealment and disclosure. The findings are used to develop practice and policy recommendations based on recognising social sensitivities around communicating HIV-positive status and other stigmatized attributes. Proposals are offered for developing further research, particularly comparative work which can help to clarify the impact of culture on disclosure of potentially stigmatizing personal information.

Table of Contents

Abstract	4
Table of contents	5
List of figures	11
List of tables	12
Dedications and Acknowledgements	13
Acknowledgements	13
Dedications	14
List of abbreviations	15
Terminology	17
Introduction	19
0.1 Introduction	19
0.2 Aims of the study	19
0.3 Background	19
0.4 Personal engagement with the topic	22
0.5 The structure of the thesis	24
0.6 A model of communication about HIV-positive status	27
PART ONE	29
Chapter One: Literature review	31
1.1 Introduction	31
1.2 HIV: the global and local UK pandemic	32
1.3 Shifts in the public attitude to the disease	38
1.4 Family	40
1.5 Stigma	45
1.5.1 Introduction	45
1.5.2 Stigmatization of HIV as a dirty condition and the transfer of risk factors to family members	47
1.5.3 Layered stigmatization	49
1.5.4 Discredited versus discreditable HIV attributes	50
1.5.5 The implications of HIV stigma for the participants and their responses to HIV stigmatization	51
1.6 Migration	53
1.7 HIV status disclosure and concealment	57

1.7.1 The relational contexts for disclosure and concealment of HIV-positive	63
1.8 Summary	69
Chapter Two: Methodology	71
2.1 Introduction	71
2.2 Theoretical framework	72
2.2.1 The key premises of symbolic interactionism	74
2.3 Methodology	77
2.3.1 Introduction	77
2.3.2 The origins and development of grounded theory	78
2.3.3 Rationale for using grounded theory	80
2.3.4 The key tenets of grounded theory	82
2.3.4.1 Theoretical sampling	82
2.3.4.2 Iterative design, data collection and analysis	84
2.3.4.3 Theoretical sensitivity	85
2.3.4.4 Incorporating relationality and reflexivity in grounded theory	86
2.4 Methods	90
2.4.1 Overview of study design	90
2.4.2 The Theoretical Population	91
2.4.3 Sampling	91
2.4.4 Study location	92
2.4.5 Participant access and recruitment	93
2.4.5.1 Recruitment of the KCPs	93
2.4.5.2 Recruitment of the wives and partners	94
2.4.5.3 Recruitment of workers from collaborating agencies	94
2.4.6 Ethical issues	95
2.4.6.1 Informed consent	96
2.4.6.2 Anonymity and confidentiality	96
2.4.6.3 Ensuring interview privacy	97
2.4.6.4 Risk assessment and risk minimization	98
2.4.7 Data collection procedures	99
2.4.8 Data analysis	100
2.4.8.1 Open coding	101
2.4.8.2 Axial coding	102

2.4.8.3 Selective coding	103
2.5 Assessing rigour	103
2.5.1 Credibility	104
2.5.2 Transferability	106
2.5.3 Dependability	107
2.5.4 Confirmability	107
2.6 Summary	108
PART TWO	110
Findings	112
Overview of the three findings chapters	112
Chapter Three: Disclosure of HIV-positive status	116
3.1 Introduction	116
3.2 The social contexts of disclosure	119
3.2.1 Disclosure to seek healthcare	121
3.2.2 Disclosure to HIV-positive peers	124
3.2.3 Disclosure within the family	127
3.2.3.1 Disclosure to sexual partners	128
3.2.3.2 Confiding in siblings	132
3.2.3.3 Informing the children	133
3.2.3.4 Confiding in friends	137
3.2.4 Open disclosure	139
3.3 The timing of disclosure decisions and their social contexts	140
3.3.1 Immediate Disclosure	141
3.3.1.1 Immediate Disclosure to Professionals	141
3.3.1.2 Immediate Disclosure within Families	142
3.3.2 Disclosure postponement	143
3.3.3 Deferred Disclosure to Children	145
3.4 Summary	149
Chapter Four: Concealment of HIV-positive status	152
4.1 Introduction	152
4.2 Concealment motivations and strategies	155
4.3 The social contexts of concealment	162
4.3.1 Protecting elderly parents	162
4.3.2 Protecting young children	169
4.3.2.1 Concealing parental HIV-positive status from children	170
4.3.2.2 Concealing children's own HIV status from them	176

4.3.3 Concealment from friends	179
4.4 Summary	183
Chapter Five: Exposure of HIV-positive status	186
5.1 Introduction	186
5.2 The social contexts of exposure	190
5.3 Uncovering the secret through other people or cues about HIV infection	194
5.4 When the perceived HIV status exposure occurred	199
5.4.1 Exposure of suspected HIV-positive status	203
5.4.2 Rapid post-diagnosis exposure of HIV-positive status	205
5.4.3 Slower exposure of HIV-positive status	206
5.5 Making meaning of perceived exposure of HIV-positive status	208
5.5.1 Uncertainty about exposure of HIV-positive status	209
5.5.2 Perceptions of Intentions underlying exposure of HIV-positive status	213
5.5 Summary	215
Chapter Six: Discussion and Conclusions	217
6.1 Introduction	217
6.2 Study overview	217
6.3 Review of the main findings in relation to previous research	223
6.3.1 Disclosure of HIV status	223
6.3.2 Concealment of HIV status	229
6.3.3 Exposure of HIV status	236
6.3.4 Relevance of the theory of communication about HIV status to other stigmatized conditions	239
6.4 The strengths and limitations of the study	241
6.4.1 Study strengths	242
6.4.2 Study limitations	245
6.4.2.1 Methods limitations	245
6.4.2.2 Sampling limitations	247
6.5 Reflections on the challenges of conducting the study	250
6.6 Possible implications of the research for policy and practice	255
6.7 Recommendations for future research	259
6.8 Summary	262
6.9 Conclusions	264

Appendices	269
Appendix 1: Study flier	269
Appendix 2: Response form to invitation to consider taking part in the study	270
Appendix 3: Study information sheet (KCPs)	271
Appendix 4: Study information sheet (KCPs partner)	275
Appendix 5: Study information sheet (workers from collaborating agencies)	279
Appendix 6: Interview consent form	282
Appendix 7: Demographic questions (KCPs)	283
Appendix 8: Interview guide (KCPs)	284
Appendix 9: Demographic questions (KCPS partner)	285
Appendix 10: Interview guide (KCPs partner)	286
Appendix 11: Interview guide (workers from collaborating agencies)	287
Appendix 12: Table illustrating the initial open coding process	288
Appendix 13: Table illustrating further open coding process	289
Appendix 14: Table illustrating axial coding around category on morality, blame and accountability	290
Appendix 15: Memo [(12 April 2011) KCP1]	291
Appendix 16: Sample field notes	292
Appendix 17: List of organisations contacted to facilitate participants access and recruitment.	293
Appendix 18: Demographic details of the KCPs and their partners	294
Appendix 19: School of Human and Health Sciences Research Ethics Panel (SREP) approval letter	295
Appendix 20: HIV awareness campaign imagery used in the UK in the early 1980s	296
Appendix 21: The Australia grim reaper Aids Campaign of 1987	297
Appendix 22: HIV awareness billboard in Kisumu, Kenya, in the early 1990s	298

Appendix 23: Stigmatizing Kenyan newspaper headlines regarding HIV during the early 1980s	299
Appendix 24: Summary of the main findings for member checks (Page 1)	
Appendix 24: Summary of the main findings for member checks (Page 2)	300
Appendix 25: A sample interview transcript.	302
Bibliography	322

Word count: 95,347 words excluding appendices.

List of Figures

Figure 0.1: A model of the research participants' decision-making about disclosure of their HIV-positive status	27
Figure 3.1: Multiple relationships between disclosure, concealment and exposure	117
Figure 4.1: Multiple relationships between disclosure, concealment and exposure	153
Figure 5.1: Multiple relationships between disclosure, concealment and exposure	187
Figure 6.1: A model of research participants' decision-making about disclosure of their HIV-positive status	220

List of Tables

Table 1.1: HIV epidemic by world region by 2012	35
Table 1.2: HIV prevalence in East Africa and the UK Among people aged 15-49 years in 2011	36
Table 3.1: Reported disclosure and the disclosure recipients	118
Table 4.1: Reported concealment	154
Table 4.2: Demographic details of children in each family unit represented in the present sample	171
Table 5.1: Reported exposure and the perceived exposer	189
Table 5.2: Perceived timing of first exposure	201

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Dedication

I dedicate this thesis to my grandma, Claris who laid my educational foundations, and my late sister Claris, whose last moments I could not be party to because I was holed up in Europe pursuing further studies. I wish you had lived long enough to witness the end of what became lengthy but instructive journey.

List of abbreviations

AIDS – Acquired Immunodeficiency Syndrome
ARV – Antiretroviral drugs
AVERT – UK based International HIV and AIDS charity
BHIVA – British HIV Association
BME – Black and other minority ethnic communities
CD4 – Type of white blood cells
CDC – Centers for Disease Control and Prevention
CROI – Conference on Retroviruses and Opportunistic Infections
DH – Department of Health (UK)
EPP – Enfield People’s Project
HAART – Highly Active Antiretroviral Therapy
HIV – Human immune deficiency syndrome
HPA – Health Protection Agency
IOM – International Organization for Migration
IPA – Interpretive Phenomenological Analysis
KCP – Key contact person (the man living with HIV)
KCPW – Key contacts person partner (or wife)
LGBT – Lesbian, gay, bisexual and transgender
MDG – Millennium Development Goals
MHF – Missouri Mental Health Foundation
MSM – Men who have sex with men
MTCT – Mother to child transmission
NAM – National Aids Map (Aidsmap)
NAT – National Aids Trust (UK)
NHS – The National Health Service (UK)
NICE – National Institute for Health and Care Excellence
OECD – Organization for Economic Cooperation and Development
ONS - Office of National statistics (UK)
OPAM – Organisation for Positive African Men (UK)
OPSI – Office of Public Sector Information (UK)
PhD – Doctor of Philosophy

PHE – Public Health England

PMTCT – Prevention of Mother to Child Transmission

SREP – School of Human and Health Sciences Research Ethics Panel

THT – Terrence Higgins Trust (UK)

UAAF – Uganda Aids Action Fund (UK)

UK – United Kingdom

UN – United Nations

UNAIDS – United Nations joint programme on HIV and AIDS

USA – United States of America

VMMC – Voluntary Medical Male Circumcision

WHO – World Health Organisation

Terminology

One of the key decisions in the present study concerned the study population, in relation to the question of who is Black African? The term Black African as used in this study reflects a perceived self-identity by people who trace their lineage to the continent Africa. The present author assumed that the participants all identified with the term. As people living with HIV, the participants were probably used to being referred to as Black Africans because it is the term used in all HIV prevention initiatives targeting the study population in the UK. Daley (1998) noted that Black Africans in the UK, compared to other minority ethnic groups, were from very diverse socioeconomic backgrounds because they potentially came from 53 different countries. Yet the term is used for data collection across all government departments and in research in a manner that suggests a homogenous population (Agyemang et al., 2005). Its use in the present thesis is limited to recent immigrants. However, the writer fully acknowledges that Black Africans in the UK go beyond the first generation, with a large population born in the UK (Prost et al., 2008). Moreover, in relation to immigrants, the term lumps together those originating from an entire continent, itself highly diverse. By focusing on East Africa, the present researcher tried to identify the participants from a specific geographical and cultural space within Africa. This choice allowed the researcher to draw upon his own familiarity with the region in which he was brought-up.

INTRODUCTION

INTRODUCTION

0.1 Introduction

This thesis offers an investigation into the ways in which HIV-positive immigrant Black African men living in the UK, and their partners, manage the flow of communication about their HIV-positive status. In this introductory section of the thesis, I will outline the overall aims of this research and consider the background and context, highlighting the knowledge gap before considering my personal engagement with the subject matter. Finally, I will outline the structure and the chapters of the thesis before giving a preview of the model of communication about HIV-positive status that was developed from the present study.

0.2 Aims of the study

The study had two related overall aims, the first of which was to gain insight into what it means for immigrant heterosexual Black East-African men resident in London, and their families, to live with diagnosed HIV. The second aim was to explore the multiple perspectives of the family members and workers from HIV-related service provider agencies about access to, and the quality of, the health and social care services aimed at such families; and to explore ideas about how such services might be improved.

0.3 Background

Since 1984, when HIV was identified as the cause of AIDS (AVERT, 2013), millions of people have acquired the disease worldwide. By the end of 2012, approximately 35.3 million individuals were living with HIV (UNAIDS, 2013c), making this a lingering global public health challenge. Sub-Saharan Africa is the worst affected region, being home to over 70% of the world's HIV cases (UNAIDS, 2012b). Globally, and in sub-Saharan Africa, women are the most affected by HIV (UNAIDS,

2012b) because of their physiological differences, social gender inequality, their role in childbearing and power imbalance in their interactions with men (Lynch, Brouard, & Visser, 2010). In the Western developed nations, men who have sex with men (MSM) and injecting drug users were initially the most affected population groups (UNAIDS, 2012c). However, heterosexual Black Africans now form the other key population group affected by HIV in the most developed nations (Prost et al., 2008). In the UK, Black Africans, mainly immigrants from sub-Saharan Africa, are the heterosexual group most affected by the disease (Forde & Cook, 2013), hence the focus of the present study. The high HIV prevalence among immigrant Black Africans in the UK has provided the context for policy developments concerning access to treatment and support, as will be discussed further in Chapter 1, the literature review.

HIV is still a killer disease in much of sub-Saharan Africa because access to treatment and care is not yet universally provided for those in need, for various reasons beyond the scope of this study, and people continue to die of AIDS related illnesses in that region (Larkan, 2011). The greatest global achievement in the fight against HIV has been the introduction of highly effective antiretroviral treatment (HAART) which has significantly reduced HIV-related morbidity and mortality, thereby improving survival rates for people with HIV who are undergoing treatment. Such individuals, particularly in rich Western nations, can now aspire to live a normal lifespan (Samji et al., 2013). HIV has thus been transformed from a death sentence (J. H. Bourne, 1999) to a long-term condition (Broder, 2010; Cooper, 2008) for those with access to potent treatment and care, enabling them to now live much longer with the condition. Consequently, the care issues associated with HIV last longer for the affected families (Bor & Du-Plessis, 1997), leading to different effects on and responses from family members (Bor, DuPlessis, & Russel, 2004). For instance, HIV-positive diagnosis can cause families to either drift apart or unite to support each other (Larkan, 2011; Murphy, Roberts, & Hoffman, 2004). Family support remains vital for the longer term well-being of HIV-positive individuals, as will be discussed in the section on family coping in Chapter 1. However, there has been limited research on the impact of HIV on affected families. Most studies conducted prior to the advances in treatment focused on the HIV-positive individuals (Bor &

Du-Plessis, 1997), not their families. After the introduction of combination therapy in 1996, research focused on women and children (Madiba, 2013; Winston, 2006). In developed societies such as the UK, HIV has been viewed as a disease of men who have sex with men (MSM) and injecting drug users (Pequegnat and Bray, 2012); and, in consequence, there has been less focus on the experiences of families.

Even less is known about how families from the present study population respond to HIV as heterosexual Black African immigrants. They originated from countries where HIV is a large-scale personal and communal problem (Larkan, 2004), as discussed further in the literature review. As will also be discussed in the next chapter, most of the earlier UK-based research had focused on MSM. Studies that have focused on Black Africans living in developed societies have tended to focus on women simply because they are more likely than men to engage with research. The present study therefore aimed to fill the current gap in knowledge on how HIV-positive diagnosis affected members of immigrant Black African families in the UK, with the main focus on the perspectives of the men. The study has both a public health and a theoretical interest, highlighting family dynamics that are not well understood.

The present study findings provide insight into the experiences of immigrant men, and their partners, from East Africa. The countries in this region (Kenya, Uganda, Rwanda, Burundi and Somalia) are themselves highly diverse. The researcher, himself an immigrant from this region, chose East Africa because of his familiarity with its socioeconomic, political and historical background and fluency in some of its main languages. The choice of East Africa was also an acknowledgement of and response to the tendency by professionals and policymakers to treat sub-Saharan Black Africans in the UK as one homogenous group (Daley, 1998).

On account of the complexity and sensitivity of the study area, with little previous research to draw upon, a modified grounded theory research methodology based on the work of Strauss & Corbin (1990) was adopted. This approach was underpinned by a symbolic interactionist theoretical framework (Blumer, 1969) which was used to explore the perspectives of the participants and their responses to HIV arising from their social interactions, as will be discussed in Chapter 2, which is concerned with methodology and methods. To enable the participants to fully

describe their perceptions, the researcher used in-depth interviews with 23 participants for data collection. Details will be discussed in the account of the research methods offered in Chapter 2.

A substantive theory of communication about HIV status that was developed from the present study is outlined below and will be discussed in detail in the findings chapters. The next section considers the researcher's motivation for undertaking the present study.

0.4 Personal engagement with the topic

This research is the culmination of my life experiences and research interests. Between 1999 and 2005, I was a reasonably effective and contented expatriate high school science teacher in Botswana. One of the few African countries devoid of political turmoil, it is economically stable and has functional support systems, including free healthcare modelled on the British NHS. However, Botswana also has one of the highest rates of HIV in the world, far in excess of that found in East Africa. The roadside billboards, the narratives about HIV and the personal observations were reminiscent of what I had left behind in Kenya. Every time a colleague, a friend or a student lost a loved one, HIV seemed to be the usual suspect. One disturbing observation was the grieving grandparents cuddling their orphaned grandchildren, many innocently oblivious to the world around them. A number of my students lived with their extended families, which to an outsider might look like a classic African extended family system. However, this arrangement often resulted from necessity after the loss of parents to HIV.

I became involved in HIV awareness initiatives aimed at reducing the infection incidence. The key message we relayed to our audience, mainly students, was, *'know your status and if positive, get free treatment'*. This was, in retrospect, too simplistic. It did not take into account family life and culture, beyond merely collecting medication from the clinic. One early morning in 2004, my involvement in HIV awareness was put to the test. A student in my class had tested HIV-positive and needed support in dealing with her situation. Although I did my best, I felt that my response to her situation was inadequate. I remember asking the student if she

had told anyone else about her infection. It turned out I was her first confidant beyond the clinical staff, making my response particularly important. I advised her not to tell other students or teachers, in order to avoid stigmatization and gossip around the school. I also suggested that she told her grandmother, her only guardian, only when and if she felt ready to do so. Classroom life for the student remained as normal as possible thereafter, while she and I did our best to keep her secret from the rest of the class. That encounter with the student marked the beginning of a journey to this PhD.

I quit teaching in September 2005 and relocated to England to pursue a Masters degree in Public Health. After completing my studies, I was employed by the Terrence Higgins Trust, the largest HIV charity in the UK. I quickly learnt that heterosexually-acquired HIV in the UK was mainly a sub-Saharan African problem. I belonged to a high-risk population and was thereby a target for HIV prevention in the UK, the focus of my own work. However, unlike in Botswana or Kenya, there was an apparent apathy towards HIV testing by Black Africans in the UK, despite the availability of free treatment. I wondered why Black Africans were apparently not using all the available resources, considering that some of them came from settings with acutely inadequate healthcare. But as an immigrant, I had also experienced some of the socioeconomic challenges facing immigrant Black Africans, such as loneliness, ignorance about the health and social care system, joblessness, lack of access to public resources and a persistent outsider status, worsened by obvious ethnic and cultural differences from the majority White British population. I struggled to conceptualise what it might mean to live with diagnosed HIV in the UK, in addition to all the other challenges so familiar to me.

I facilitated several HIV awareness sessions involving Black Africans in the UK. The key messages concerned the need for timely testing, because those who did so stood a better chance of living a near normal lifespan. However, I wondered what went on in the families in which some of my HIV-positive audience members were living with partners and children. In doing the study, I drew upon my personal experiences as an immigrant Black African, as well as previous research experience in the UK involving Black Africans; my personal experiences in the UK, Botswana and Kenya; and my public health training. In all the social contexts in which I had

lived, the key HIV message was about getting tested, knowing one's HIV status and, if positive, getting treatment. The focus in the UK and Africa was mainly on potentially infected individuals and - not their families. This consideration provided the rationale for the present study. It seemed to me that in the UK, HIV had become normalised because of freely accessible potent treatment and the efforts to destigmatize the condition. Potentially infected individuals are expected to get tested, to access treatment if necessary, and to live 'normally'. But little is known about what normal living means for the affected families, particularly those who face other complex issues arising from cultural differences and fragile social status. While conducting the study, I drew inevitably on my personal and professional experiences, but strove to allow the study to be fully informed by the participants, rather than my own presuppositions. I relied on a rigorous study design, my experience in conducting qualitative research and the shared cultural background with the participants to enable me to draw very rich data from the interviews with the study informants. The following section outlines the structure of the thesis.

0.5 The structure of the thesis

This thesis is organised into two parts. Part One addresses the background for and methodology used in the study; and consists of two chapters. Chapter 1 will review the relevant published literature. In adherence to the principle of theoretical sampling in grounded theory, discussed in Chapter 2, the choice of topics to be covered in the literature review was guided by the key findings from the study and organised around the core category of communication about HIV status and related concepts such as stigma, family and immigration, all of which affected the participant's decisions regarding communication about their sero-status. A summary of how the major categories of disclosure, concealment and exposure were all interrelated and affected the way participants perceived and responded to communication about their HIV status is provided below.

Chapter 2 focuses on the study methodology and methods. This chapter is divided into four sections. The first section introduces the Chapter and the second section discusses the theoretical framework of symbolic interactionism that underpinned the

study, and its application in the present study. The third section reviews the choice and application of modified grounded theory, as expounded by Strauss and Corbin (1990), as an appropriate methodological approach to understanding at least some of the research participants' major concerns. The fourth and longest section of the chapter focuses on the specific methods used in the study. It outlines the study design, access to and recruitment and the profile of respondents; the management of ethical issues, in-depth interviewing as the data collection method, the approach to data analysis and how the researcher ensured rigour to achieve quality research.

The second part of this thesis addresses the findings, discussion and conclusions. After a short preface, the findings are then presented in three interrelated chapters, each dedicated to one of the three major categories that emerged from the present study, namely, disclosure, concealment and exposure. The first findings chapter, Chapter 3, discusses disclosure of HIV-positive status. Disclosure refers to the conscious and deliberate effort by an HIV-positive individual to reveal their sero-positive status to people through choice. Qualitative extracts from the interviews are used as evidence to illustrate the dilemma faced by most of the respondents regarding disclosure of their HIV status, the social contexts of HIV status disclosure and the reasons given for disclosing their status. Crucially, four of the 18 respondents had 'come out' and revealed their HIV status to their family members, other social contacts and public audiences at HIV awareness gatherings. Fourteen of the 18 research participants carefully selected the people they told about their sero-positive status, or the status of the partner in the case of the HIV-negative man, on the basis of estimates of the likelihood of them responding in a supportive and non-stigmatizing manner. Their disclosure decisions were shaped by need. If individuals in this, the largest group of respondents, did not anticipate any benefit from revealing their HIV status, then they attempted to conceal it, the focus of Chapter 4. The term 'concealment' was preferred to that of 'non-disclosure', most commonly used in the relevant literature, for reasons discussed in Chapter 1. Concealment is used to refer to deliberate efforts by the HIV-positive individual and/or family members to hide their sero-positive status from specific people within their social networks. Chapter 5 will explore the research participants' experiences of, and concern about the risk of, exposure. Exposure was a risk which troubled the

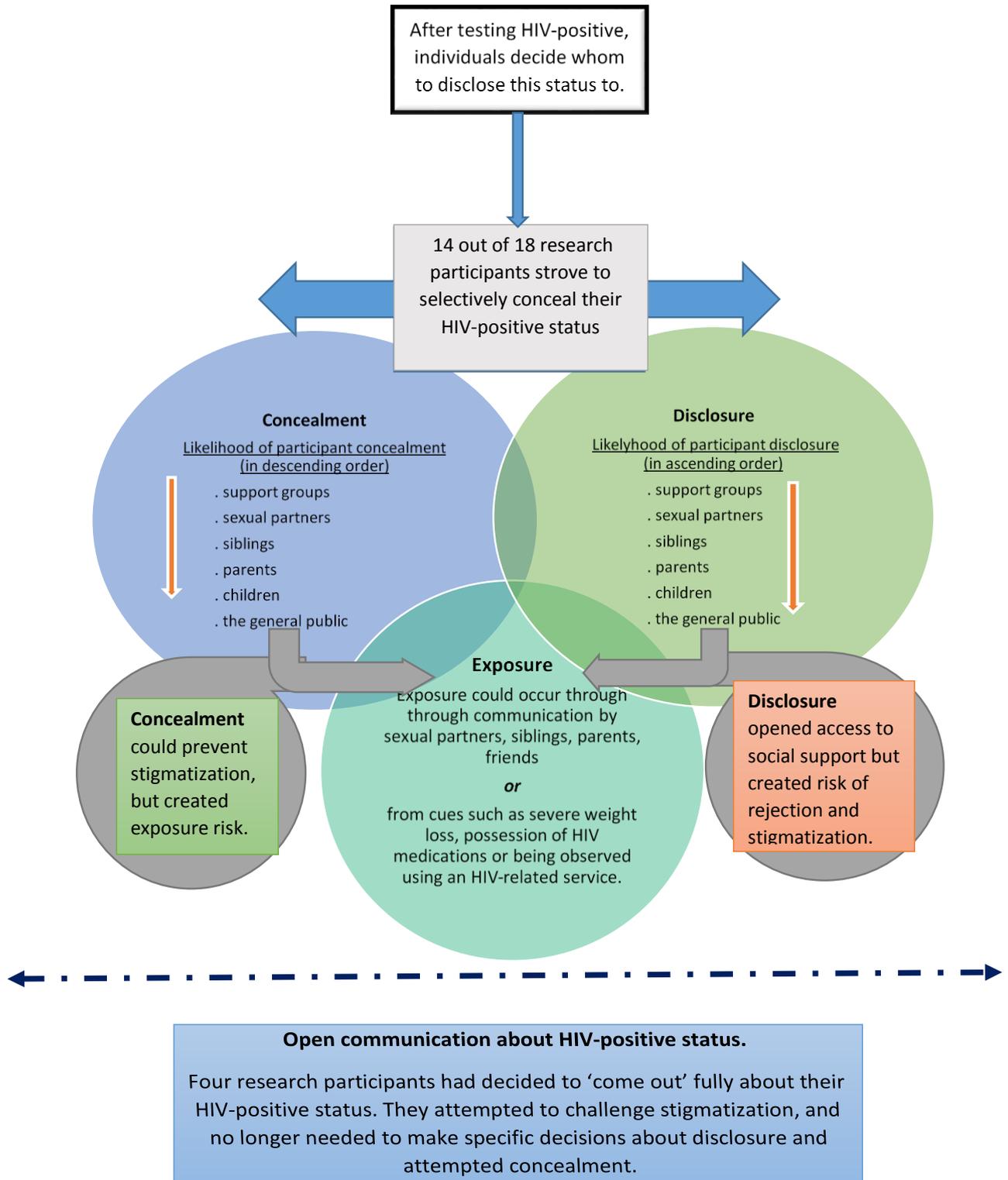
majority of the participants, involving the unwanted revelation and loss of informational control. Those who have 'come out' publicly avoid this concern.

Chapter 6 will discuss the findings of the present study in relation to the chosen methodology. The study strengths and limitations, and key challenges encountered while undertaking the study, will be considered. The main findings will be reviewed in relation to the extant literature, the implications for policy and practice will be considered and recommendations for future research will be suggested.

0.6 A model of communication of HIV-positive status

One of the main concerns for the men and their families was managing the flow of information about their HIV-positive status. The present study found that, except in the case of four participants who had become open about their sero-status, these men and their family members faced an ongoing dilemma regarding whether, to whom and when they should disclose this status. Although disclosure could unlock family and other social support, it also carried the risk of rejection for the present study population, who already risked stigmatization because of other attributes, such as uncertain immigration status, racism and low socioeconomic standing. Those who opted to conceal their HIV-positive status from members of their social networks therefore missed out on potential sources of support as they could not predict the responses they would get if they irreversibly disclosed their status to particular others. Such individuals were therefore trapped in what Heyman et al. (2013) have called the 'inductive prevention paradox'. The key concern for the relevant participants was losing control over the information about their positive diagnosis, because once someone else learnt of it, this knowledge could never be unlearned. Consequently, most of the participants selectively disclosed their HIV-positive status only to certain individuals; while concealing it from others, including some of their own family members. Figure 0.1 below provides an overview of the participants' responses, which will be discussed in detail in the three findings chapters.

Figure 0.1. A model of the research participants' decision-making about disclosure of their HIV-positive status.



As illustrated in Figure 0.1, the research participants' decisions regarding communication about their HIV-positive status could be categorised as either selective or open. As outlined above, the four participants who openly discussed their condition had overcome the barriers that led the remaining 14 participants to attempt to selectively conceal their HIV status. Those respondents who selectively concealed their HIV status faced a constant risk, which concerned them greatly, of exposure through cues or communication – either intentional or unintentional - by others who knew that they were living with HIV. By selectively revealing their status, they could potentially access social support but they also risked rejection and exposure because their confidants, or their own circumstances, could reveal their condition at any point, as outlined above, and as discussed further in the findings chapters.

PART ONE

BACKGROUND AND **METHODOLOGY**

CHAPTER ONE. **LITERATURE REVIEW**

CHAPTER ONE. LITERATURE REVIEW

1.1 Introduction

As outlined in the Introduction to the thesis, the aims of this study were to explore what it means for immigrant Black East-African men and their families resident in London to live with diagnosed HIV; and how services could be improved to meet the needs of such populations. The thesis is organised around an important emergent issue, namely concerns regarding communication about HIV-positive status. The study findings show that four of the participants had become HIV awareness activists and were happy to reveal their HIV status, while the other 14 participants sought to conceal their positive diagnosis from certain others, including friends and family members, in order to minimise their risk of stigmatization. This literature review is therefore built around these key findings, in accordance with the principles of grounded theory methodology.

The participants' decisions to share the information regarding their positive diagnosis were embedded in wider societal, cultural and family factors. The current chapter presents a critical review of published research on the issues that this researcher identified as the most relevant to how the participants attempted to manage information about their HIV-positive status. The present research topic traverses a wide range of issues, too many to be considered separately in this review, necessitating the researcher's selection of the issues that are most pertinent to the theory emerging from the study of communication about HIV status. The review will focus on HIV/AIDS epidemiology, family, stigma, immigration, and HIV status disclosure and concealment. Although most of the published literature tends to discuss non-disclosure, the present findings illustrate a more active process of concealment. I have therefore opted to use the latter term due to its relevance to the present findings. Other relevant issues, such as medication side-effects, the criminalization of HIV transmission, transnational citizenry, culture, risk, multiple

sexual partnerships, religion and socioeconomic status, will be considered more briefly in relation to the topics around which the literature review is organised. There is limited extant UK-based research into the impact of HIV on immigrant Black African men and their families on which to draw. Related research from other countries or other stigmatized conditions will be drawn upon where available and relevant.

1.2 HIV: the global and local UK pandemic

This subsection reviews literature on the Human Immunodeficiency Virus (HIV) in relation to the similarities and differences between the epidemiology of the disease in East Africa and the UK, and also the connection between the two epidemics which has resulted from migration. However, both the epidemic itself and the ways in which it is recorded change often, making it difficult to disentangle the two. Historical or inter-country comparisons, for example, may be distorted by changes in data collection methodology. HIV data availability is most challenging in resource-limited settings with less developed surveillance systems, resulting in a reliance on mathematical modelling to estimate the scope of the disease in East Africa. The information presented below reflects data available as at March 2014. The discussion which follows will define HIV and AIDS, review HIV epidemiology and the history of the HIV virus, and explore the link between the sub-Saharan Africa and the UK HIV epidemics.

The HIV virus affects the human body by destroying the protective abilities of the immune system. It leaves an individual susceptible to cancers and opportunistic infections (Dougan et al., 2008), that thrive on compromised immune systems. The virus mainly targets CD4 white blood cells, hence the prominence of the CD4 cell count as the benchmark in HIV management (Gazzard et al., 2008), as discussed below. When an individual's immune system can no longer protect itself against opportunistic infections, Acquired Immunodeficiency Syndrome (AIDS) sets in, and the individual becomes symptomatic (UNAIDS, 2009).

The history of the HIV epidemic can be traced back to the summer of 1981 (WHO, 2010) when unusual cases of Kaposi Sarcoma and pneumonia were detected among men who have sex with men (MSM), and then among injecting drug users, in the USA. By December of the same year, the first cases of AIDS had been documented in the UK. All the initial UK cases of HIV were linked to the American epidemic because they involved MSM with a history of sexual relationships with Americans (AVERT, 2013). At the time, HIV in most of sub-Saharan Africa was viewed as a strange disease that only affected MSM in distant countries (Mwangi, 2013). HIV/AIDS has since become a global emergency, and the focus of a United Nations Millennium Development Goal (UN, 2009). HIV has spread globally (Solorio, Currier, & Cunningham, 2004), albeit with varying prevalence and impacts. The terms HIV and AIDS are highly stigmatized (Poindexter et. al., 2013), as well as the disease, because of the cultural perceptions that link them with male homosexuality, intravenous drug use, and irresponsible risk-taking by engaging in unprotected sex and promiscuity (Larkan, 2004). HIV and AIDS thus carry moral judgements for those associated with them (Groves, Maman, & Moodley, 2012), which possibly prevents those infected (or otherwise affected) from discussing their HIV status, because they also perceive themselves in the stigmatizing lay views.

Global attempts to produce an HIV vaccine have been unsuccessful so far¹ (Haynes & McElrath, 2013). Varying biomedical, behavioural and structural prevention strategies have been adopted in different countries (Kalichman et al., 2011; Rotheram-Borus et al., 2012). Despite such efforts, millions of people have been, and continue to be, infected worldwide, as illustrated below. However, the most notable global achievement against HIV has been in the development of more effective treatments, and the expansion of access to them (UNAIDS, 2012b). Highly Active Antiretroviral Therapy (HAART) was introduced in 1996 and has significantly reduced HIV-related mortality and morbidity worldwide. Testing people early and treating those infected to prevent onward transmission have become global aims

¹ Researchers reported at the 20th Conference on Retroviruses and Opportunistic Infections (CROI -2013) that a 26 month-old girl who commenced anti-HIV treatment 30 hours after birth had been cured. The same report also refers to a previous case in which an adult infected by HIV was cured through a bone marrow transplant in Germany

(Gupta et al., 2013) but inter and intra-country disparities in access to treatment, especially between richer and poorer nations (UNAIDS, 2012; UNAIDS, 2008), has slowed down progress. Limited access to treatment and care in some resource-limited countries in sub-Saharan Africa means that HIV is still a death sentence for those without access to treatment, exacerbating stigmatization of the disease and those infected in these settings.

HAART treatment has its drawbacks, one being that it is very costly (Mandalia et al., 2010), which partly explains why it is not yet universally available in some East-African countries. In the UK, for example, the 2012 cost estimate indicated that the NHS would spend approximately £360,000 on HAART alone, excluding social care and staff time, to care for an HIV-positive adult over their lifetime. Although the cost of HIV treatment in Sub-Saharan Africa is much lower than that in the UK due to global initiatives such as the Global Fund which subsidize the cost of treatment in poorer nations, HIV treatment remains expensive even in sub-Saharan Africa. At public health level, many governments in Sub-Saharan Africa still heavily rely on foreign sources of funding to sustain their HIV treatment programs. At individual level, treatment related costs such as the cost of transport to access services can be very prohibitive for some individuals, as the present findings will illustrate. HAART also has significant side-effects, as outlined below. Treatment fails for some people, and can result in the development of resistant virus sub-strains (Smith et al., 2010; Taiwo, Murphy, & Katlama, 2010). These factors make daily life for some people with HIV challenging in ways which are not always well-understood.

According to UNAIDS (UNAIDS/WHO, 2013), around 35.3 million people had been infected worldwide by the end of 2012, as illustrated in Table 1.1 below.

Table 1.1. HIV epidemic by world region, 2012

Region	Adults & Children living with HIV	Adults and children newly infected	Total AIDS deaths	Adult prevalence %
Sub-Saharan Africa	25.0 million	1.6 million	1.2 million	4.7%
South and South-East Asia	3.9 million	270 000	220 000	0.3%
East Asia	880 000	81 000	41 000	0.1%
Latin America	1.5 million	86 000	52 000	0.4%
North America	1.3 million	48 000	20 000	0.5%
Western and Central Europe	860 000	29 000	7600	0.2%
Eastern Europe, Central Asia	1.3 million	130 000	91 000	0.7%
Caribbean	250 000	12 000	11 000	1.0%
Middle East and North Africa	260 000	32 000	27 000	0.1%
Oceania	51 000	2100	1200	0.2%
Total	35.3 million	2.3 million	1.6 million	0.8%

The majority of those infected by HIV globally reside in sub-Saharan Africa, as shown above. But the sub-Saharan African HIV epidemic has a direct bearing on the UK epidemic because the widespread political and economic instability in the region has led to sustained immigration to the UK over the past two decades (Stewart, 2008). Prior to this, HIV in the UK was mainly confined to MSM and injecting drug users (Bingham, 2002). Most of the heterosexually-acquired HIV in the UK, concentrated among Black African immigrants, was probably contracted in sub-Saharan Africa (Fisher & Delpech, 2009; HPA, 2008). About 32% of the 98,400 people living with HIV in the UK by 2012 were African-born women and men (Aghaizu et al., 2013). According to Public Health England (2013), about 5% of those living with HIV in the UK by the end of 2011 were from East Africa; Burundi, Kenya, Rwanda, Somalia, Tanzania and Uganda. About 65% of the HIV-positive East-Africans were females, whereas 35% were men, reflecting the gender distribution in their countries of origin. Available data show great variation in HIV prevalence between and within the participants' native countries and the UK, as illustrated by the table below.

Table 1.2. HIV prevalence in East Africa and the UK among people aged 15-49 years in 2011 (UNAIDS, 2013b)

Country of origin	National HIV prevalence (%)
Somalia	0.7
Burundi	1.3
Rwanda	2.9
Kenya	6.2
Uganda	7.2
Regional average prevalence	3.7
United Kingdom	0.3

As illustrated here, the average adult HIV prevalence rate in the East-African countries where the present participants originated was 3.66% by 2011 (UNAIDS, 2013a). Somalia, with the lowest adult HIV prevalence in the region, as shown above, had more than double the UK adult prevalence of 0.3%. HIV prevalences in East Africa do not correspond to those found among immigrants to the UK. HIV prevalence among East-Africans living in the UK has been estimated to be 1.3% (PHE, 2013), less than half of that found in the region of origin. Differences in prevalence and treatment availability may be associated with variations in the impact of HIV and in the meanings which people attach to it, as discussed in the Findings chapters.

One of the biggest challenges to the global effort to halt the spread of HIV is getting people to test for the virus soon after infection (Cherutich, Bunnell, & Mermin, 2013; Musheke et al., 2013). Individuals are categorised as late testers if they test for HIV when they already have an AIDS defining illness, or when their CD4 cells count is below the threshold at which it is considered treatment ought to begin (BHIVA, 2012; Forde & Cook, 2013; Mukolo, Villegas, Aliyu, & Wallston, 2013). However, this threshold varies between countries. For example, the latest USA guidelines recommend commencement of HIV treatment at between 350 to 500 CD4 cell count (Gupta et al., 2013). In the UK, an individual is considered a late tester if they screen for HIV with CD4 cells counts <350 within three months of the diagnosis (Aghaizu et al., 2013). Members of the present study population diagnosed with a CD4 cell count below 300, even without any other health condition, would be considered very late in the UK (Forde & Cook, 2013), whereas they would possibly not be considered for urgent treatment if they were diagnosed in their country of origin. Such differences potentially affect how members of the study population view their health and their decisions about accessing healthcare.

The latest HIV epidemiological data showed that about 98,400 people were living with HIV in the UK at the end of 2012. Black Africans were the second most affected group, after MSM (Aghaizu et al., 2013). Black Africans were the largest heterosexual group affected by HIV, both in the UK and in the whole of Western Europe (Prost et al., 2008). About 47% of all new HIV diagnoses in the UK in 2012

were considered late (Aghaizu et al., 2013). Late diagnosis in the UK was most common among Black Africans, particularly men. Some of the reasons for late diagnosis among Black Africans include slow entry into the UK health system, inadequate knowledge about the health system, misconceptions about risk of deportation for testing positive (Dodds et al., 2008) and fear of stigma (Stutterheim et al., 2012). Late diagnosis among Black Africans can also be attributed to the timing of their infection. Most of them were infected in their countries of origin (Fisher & Delpech, 2009). On arrival in the UK, HIV was often not their primary concern and they may test for HIV only when they became ill. In relation to the present study, 10 of the 18 research participants said that they had been diagnosed with HIV after developing AIDS-defining illnesses such as TB, pneumonia, Kaposi Sarcoma, severe weight loss and/or mental health concerns. Two of the 11 HIV-positive men were diagnosed in Africa. All six of the women were diagnosed in the UK. Fifteen of the 18 participants believed they had been infected in their native countries, suggesting that many black Africans in the UK were infected outside the UK as previously reported (Forde & Cook, 2013).

The following subsection reviews the literature on the transformations undergone by the UK HIV epidemic and, firstly, the public attitudes towards the disease.

1.3 Shifts in public attitudes to the disease

It has been argued that, in the UK and other developed countries, perceptions of HIV have undergone three social transformations (Kingham, 1998). In its early phase, HIV was generally seen as a disease of others, MSM, injecting drug users and haemophiliacs, because the heterosexual white British population did not perceive themselves to be at risk of infection. But between 1983 and 1987, HIV became a “possibly us” disease, as evidence accumulated that heterosexual populations were becoming infected because bisexual men and intravenous drug users were passing on the infection to their heterosexual partners. However, the spread of HIV to the general UK population, as depicted by the iceberg campaign (Appendix 22), turned out to be much slower than had originally been feared, and HIV became a distant threat for white British heterosexuals after 1991 (Kingham,

1998, p. 127). HIV in the UK remains mostly confined to the sub-populations outlined above. The present participants live in a society in which HIV is again viewed as largely an outsider disease brought in by the socially marginalized. But they originated from countries where HIV infection was moralized and generally perceived as a punishment for an individual's sins (Braid, 2001). Idemudia and Matamela (2012) argue that many Africans attribute incurable diseases to the acts of evil people or gods. In the UK, HIV is still largely viewed as a gay disease, save for heterosexual Africans who have imported the condition into the UK. Such societal attitudes towards HIV influenced the way the present study population perceived and managed their life with HIV, as well as their access to and use of HIV services in the UK, as will be discussed in the findings chapters.

Social and political responses to HIV in the UK have led to legislative changes. Knowingly infecting another through sexual intercourse without their informed consent became a criminal offence. Irrespective of the preventive goal, the criminalization of HIV transmission may have heightened caution in revealing HIV-positive status. The majority of those convicted in the UK so far have been Black African men (Carter, 2004), leading to further stigmatization of the study population. It is not known why the majority of those jailed have been Black Africans, but most of the prosecutions so far have involved heterosexual relationships. Black African men are the heterosexual group most affected by HIV, and may therefore be more likely than their white counterparts to be represented in criminalization cases. Covert racism may be another factor.

Responses to the epidemic in Sub-Saharan Africa have also shifted during its brief history. In Kenya, for instance, the early days of the HIV pandemic witnessed media headlines such as 'horror sex disease', and contracting HIV was viewed as a death sentence (Mwangi, 2013). At the time, HIV was only known to affect MSM in Western nations and the cause was initially unknown. But fear, confusion, anguish and uncertainty about the mysterious disease began to grip the country as the heterosexual infection rate rapidly increased. Those infected died quickly from AIDS. Their burials were rushed and the causes of death were shrouded in secrecy, with corpses draped in plastic bags because of a misplaced fear that the infection could spread from them. By the early 1990s, policy responses and prevention

initiatives were in place. The media were sensitised to stop the sensational coverage enhancing HIV stigma and HIV was no longer viewed as an 'outsider disease'. Those infected needed support (Mwangi, 2013).

This section has demonstrated that the general British public attitude towards HIV remains detached and HIV is largely viewed as a 'boxed' stigmatized disease of Black Africans, MSM, and injecting drug users. However, in sub-Saharan Africa, HIV is often viewed as a result of heterosexual promiscuity. The interaction of these two perspectives affected the way the participants managed the information about their diagnosis, as will be discussed in the Findings chapters. The next section focuses on family.

1.4 Family

This section defines the concept of family as it is applied in the present study, and reviews the significant literature on the impact of HIV on families. As discussed above, HAART has transformed HIV into a chronic manageable disease but improved prognosis for those infected who have access to treatment also means that affected families live longer with the known and unknown consequences of HIV and its treatment. However, little is known about the impact of HIV on the families of this study population, or how they respond to a family member's HIV-positive diagnosis. The present study focused on immigrant men who came from different countries, each with its own diverse socioeconomic and political cultures; and relocated to another socioeconomically and culturally very diverse country. Their understandings of family were likely to encompass all their experiences of the dominant models of family in both their countries of origin and the UK.

Understanding family in the context of the present study population was challenging because of these multicultural interactions outlined above and the diversity of contemporary Western forms of family (Muncie & Sapsford, 1997; Edwards, 2008), the paucity of related literature and the lack of a universal definition of the term 'family' (Wilson, 2012). Le Poire (2006) argued that defining the term is problematic because people are so familiar with the notion that they don't really think about its

meaning. Weigel (2008) argued that the concept of family is socially constructed, learnt through a combination of wider societal framing and individual experience.

Friedman (1998) defined family as a unit of interdependent and interacting individuals, mostly related through marriage or adoption, who carry out various functions relevant to their roles. Similarly, Ferrari et al (2005) defined family as individuals with a shared bond or a sense of belonging through blood relationships, marriage, adoption, legal ties, or long term commitments. However, interdependence and long-term commitment are now less clearly attributes of family than they used to be, as family fragmentation and divorce are now both more common. Wilson (2012) defined family as referring to a group of people related biologically or legally who live together or associate with one another with the shared aims of providing food and shelter and rearing children. However, this definition excludes families without biological or legal relationships and emphasises procreation and dependence, discounting those families who opt to remain childless.

The working definition of family used in this thesis is a social group with special attachments to each other which nurtures its members, regulates their behaviour and evolves over time in composition and function. This definition recognises the extended kinship patterns common to African cultures. Family was a particularly important source of support for such people in the UK, where their other social networks were limited. In referring to 'family', the participants described different relations with whom they shared biological or legal links, such as biological children, adopted children, step-children, parents, sexual partners and siblings. Some also saw family friends from their native countries as members of their UK family. This kind of relationship, called fictive kin status, is common in the African diaspora and has also been reported among African Americans (Stewart, 2007). To many of the present participants, disclosure of HIV-positive status to those close to them was particularly challenging because the extended nature of family ties meant that this information could potentially be passed on to a large number of others.

Despite its diversity, family remains a vital source of social support for people living with diagnosed HIV (Dyer et al., 2012; Madiba, 2013), although the way families

respond to a member's HIV-positive diagnosis depends on their composition, structure and location. The network of family members the participants had to consider for their status disclosure in the UK was smaller than in Africa. However, the distance between the UK and their countries of origin aided the participants who chose to conceal their status from some of their family members in Africa, as will be discussed in the Findings chapter on concealment.

As noted in the Introduction, one of the main justifications for the present study was the dearth of research into the impact of HIV on family members. Pequegnat et al., (2012) argued that there has been little research on this topic because HIV has been perceived in developed countries as an illness of MSM and injecting drug users. Moreover, much of the previous research into family issues has concentrated on the impact of HIV on children and women (Bor & Du-Plessis, 1997; Bor, DuPlessis, & Russel, 2004; Madiba, 2013; Winston, 2006). The present study aimed to fill the knowledge gap by focusing on Black East-African immigrant men and their families, a group about whose concerns very little is known.

Family dynamics vary considerably, and are likely to change drastically after an HIV diagnosis is disclosed (Evans & Thomas, 2009). Both social support and family functioning can be disrupted. Generally, when individuals are diagnosed with a critical illness, the family becomes the place of solace (Bor et al., 2004). But HIV is a distinctive disease because of its stigma and the risk of onward transmission (Awiti Ujiji et al., 2010). Although five of the six couples involved in the present study were HIV-positive, they still faced the risk of cross-infection. Apart from their supportive role to ensure the wellbeing of HIV-positive individuals (Yurong et al. 2011), families can also be a source of stress and stigmatization, affecting not only how such individuals perceive HIV (Ho and Mak, 2013) but also their decisions to conceal or reveal their infection. For instance, one male participant said that he was stigmatized by his brother for being HIV-positive and their relationship was strained thereafter. Since HIV poses the risk of onward transmission, some family members may stigmatize those infected for fear of contracting the disease. Disclosure decisions are also weighed against the burden of moral accountability, because individuals' fidelity and sexual mores may be questioned.

The impact of HIV on families has been strongly affected by the implementation of HAART. However, the present participants originated from countries where treatment is not fully accessible, and HIV is potentially perceived as a death sentence for those without access to treatment. As the findings will show, most of the research participants were more likely to tell family members in the UK than in Africa that they were infected because HIV was 'treatable' in the UK, but could be a death sentence in Africa. Although concealment from family members in Africa was common, the difference in treatment availability led to some of the participants being asked by infected family members back in Africa to share the drugs that were only available in the UK. Such requests also affected the decisions of some participants regarding whether or not to reveal their HIV status to their social contacts in their native countries.

Varas-Díaz et al., (2005) noted that HIV status disclosure affects social relationships in some families. For example, parent-child communication normally plays an important role in children's nurturing (Le Poire, 2006) but HIV affects this communication in some families (Cederbaum, 2012), especially regarding HIV-positive status disclosure (Krauss et al., 2013; Madiba, 2013), as the findings from the present study will illustrate. Research (Krauss et al., 2013; Pinzon-Iregui et al., Beck-Sague, & Malow, 2012; Qiao, Li, & Stanton, 2013) shows that some parents and caregivers avoid disclosure to children because they feel that they lack the skills needed to communicate effectively with them, or in order to protect their children until they consider them old enough to handle the information. Similar findings have been reported (Idemudia & Matamela, 2012; Ueno & Kamibeppu, 2012) for disclosure of other stigmatized conditions, such as mental illness, in the family. As discussed in the section on disclosure below, determining the correct age at which to disclose to children was a challenge for many parents, including eight of the present participants. Discussions about parental sexuality are viewed as inappropriate in many sub-Saharan African social groups (Larkan, 2004). It can therefore be a prohibited subject, despite the documented benefits for the psychosocial wellbeing of not only the children but also the entire family (Qiao et al., 2013). Reticence about HIV limits the capacity of parents to mitigate the risk of children becoming affected. More generally, concealment can lead to suspicion,

distrust and emotional ill health among family members, due to stress arising from keeping secrets. HIV can completely transform family life (Jones, 2009), as the present findings will illustrate. For instance, HIV can lead to the dissolution of families through death, divorce or separation (Dyer et al., 2012) or lead to women and children becoming the heads of households in some cases (Jones, 2009).

For some families, HIV reduces household income through unemployment (Larkan, 2011; P. Taraphdar et al., 2011). Only one of the present participants was formally employed. Low income affected the entire extended families of the participants who, culturally, expected financial support from kin who had made it to Europe. For the infected family members who were still employed, job attendance could be intermittent, leading to reduced income (P. Taraphdar et al., 2011) and stigmatization at work. In the UK, legislation such as the Equality Act 2010 in England is designed to make workplaces suitable for people with long-term health problems. In addition, there is some financial support for individuals with HIV and their families (THT, 2013). Although the present participants accessed free healthcare, HIV also increased their travel costs through regular clinic and support groups visits (Nomoto et al., 2013). For three research participants, their partners in Africa had assumed full financial responsibility for their families because the participants were unable to work in the UK due to uncertain immigration status. Such partners were likely to experience stress (Krishna et al., 2005) and could expose the HIV status of their partners in the UK in order to account for their struggles, or keep it a secret so as to avoid stigma.

Despite its generally negative consequences, HIV may also have beneficial influences on some families. Scott-Sheldon (2011) argued that knowledge of the other's HIV status can lead to improved communication about sexual health among some couples, reducing the risk of onward transmission. Seven of the 18 participants said they practiced safer sex through condom use to avoid infection or cross-infection because they knew each other's HIV status. (Cross-infection refers to an HIV-positive individual acquiring a different strain of the HIV virus). Spirig (2002) noted that some families' support structures became stronger after disclosure of an HIV-positive diagnosis. Members of such families are often drawn closer to the infected individual in order to provide support and adjust to shared

risks. Studies have shown that families close to each other before diagnosis are likely to be drawn together and vice versa (Neville Miller & Rubin, 2007; Serovich, Craft, & Reed, 2012). The potential for response variation left the present participants uncertain about what to expect of their family members. They therefore carefully selected family members whom they believed were trustworthy to disclose their diagnoses to. Some were stigmatized, instead of being supported by the family members, as discussed above. The process of stigmatization itself is considered in relation to HIV in the next section.

1.5 Stigma

1.5.1 Introduction

The aim of this section is to highlight how stigma affected the ways in which the men and their families managed information about their HIV status. The section is divided into five subsections, beginning with this one, which introduces the concept and considers stigmatization as a common aspect of social life. The second subsection discusses stigmatization of HIV as a dirty condition and the transfer of HIV risk factors to family members. The third subsection focuses on public attitudes towards HIV and the resultant categorization of HIV-positive individuals into discredited or discreditable individuals, depending on how much is known about their disease. The fourth sub-section highlights how HIV stigmatization is compounded by other forms of stigma faced by the present study population in the UK. The final subsection discusses the consequences of stigmatization of HIV, and how the participants responded to it.

Stigma is the undercurrent in the present thesis, because the fear of stigmatization was one of the reasons why the men and their partners were so concerned about who knew of their positive diagnosis. As the findings will show, those participants who selectively concealed their or their partner's HIV-positive status were all worried by the risk of stigmatization. Such participants could not predict how those they concealed their diagnosis from would react to learning that they were HIV-positive, without giving up their confidentiality and risking exposure to third parties. They

faced the 'inductive prevention paradox' (Heyman et al., 2013). Those who opted to selectively conceal their condition missed out on potential sources of support, thereby creating new risks such as isolation, retreating into cocoons of secrecy.

The concept of stigma covers a number of interrelated components such as stereotyping, labelling, loss of status, power exertion and discrimination (Airhihenbuwa, Ford, & Iwelunmor, 2013). Stigma was initially defined by Ervin Goffman (1963) as a deeply discrediting attribute that reduces the bearer from being a whole usual individual to a tainted and discounted person. Stafford and Scott (1986) later defined stigma as an individual's characteristic that is contradictory to a social group's norms, and shared beliefs about an individual's expected behaviour. However, societal norms can change over time. Moreover, in multicultural societies such as the UK, a variety of norms may be accepted and values vary. Homosexuality is, for example, more highly stigmatized in sub-Saharan Africa and its diaspora (Paparini, Doyal, & Anderson, 2008) than among the native white British population, although covert forms of discrimination can still be found. Consequently, being diagnosed HIV-positive in the UK, particularly among black African men, is likely to elicit negative attitudes towards those infected because it potentially casts doubts about such men's sexuality, since HIV in the UK was initially linked mainly to MSM (Kingham, 1998). Being HIV-positive therefore carries different meanings and implications, based on how the society views HIV, and as interpreted by the infected individual and their family. The working definition of stigma used in the present study is taken from Young et al. (2013) who defined stigma as a socially and culturally embedded process through which individuals experience stereotyping, devaluation and discrimination, which can lead to harmful internalized beliefs or actions by those stigmatized, and may cause negative health outcomes (Florom-Smith & De Santis, 2012), as discussed below.

Humans naturally cluster into groups (Tajfel, 2010) and identify outsiders on the basis of perceived common and distinctive characteristics such as geography, country, shared history or culture. Scambler (2009) noted that all social groups discriminate between the normal and the abnormal and insiders versus outsiders. Stigmatization is therefore the means of distancing deviants from a group (Engebretson, 2013). It affects the perceptions and responses of both the

stigmatized and those doing the stigmatizing, as discussed below. Gagnon (2012) noted that the visibility of stigmatized conditions is a critical attribute since it affects the potential for their concealment. Members of the study population could not conceal their status as Black African immigrants who may be viewed by others as economic migrants dependent on the welfare system (Anderson, 2008b) or as benefits scroungers (Fogg, 2013). Although the participants did not exhibit any stereotypical signs of HIV, such as severe weight loss, they could easily be viewed as abnormal if someone uncovered their HIV status (Engebretson, 2013), and these two potentially stigmatized statuses could compound each other. The next subsection discusses the public attitude towards HIV as a dirty condition, an attitude that devalues infected individuals and their families.

1.5.2 Stigmatization of HIV as a dirty condition and the transfer of the risk factors to family members

Logie and Gadalla (2009) observed that the general public overall hold negative attitudes towards HIV risk factors such as sex work, injecting drug use and men having sex with men. In sub-Saharan Africa, where HIV is mainly transmitted through heterosexual sex, those infected may be perceived as morally tainted, promiscuous individuals (Stutterheim et al., 2012). However, there are millions of people worldwide who have been infected by HIV without violating any social norms, such as the clinicians infected through needle prick injury (Parkin et al., 2000), haemophiliacs infected through blood transfusion (O'Reilly et al., 2009), young people who have been vertically infected through their mothers (Awiti Ujiji et al., 2010; Santamaria et al., 2011) and, most pertinent to the present study, those infected through sexual partners. As Douglas (1966) powerfully argued, impurity and dirt acquire wider cultural significance in relation to prevailing understandings about a social order. Such negative perceptions tend to be transferred to those infected and their families, and from them to groups seen as being at risk of infection (Logie and Gadalla, 2009), including the present study population.

Family members related to those infected with HIV can be exposed to social isolation, physical violence, gossip and censure (Ogunmefun et al., 2011). HIV-positive individuals are generally viewed by the uninfected as more responsible for their infection and deserving of their fate than those with other conditions; and HIV infection is thus moralized (Bond, 2010; Groves et al., 2012). Some HIV-negative people still view those infected with HIV as dangerous and to be avoided, because of the perceived risk of onward transmission through everyday contact, despite epidemiological evidence to the contrary (Henkel, Brown, & Kalichman, 2008; Logie & Gadalla, 2009; Obermeyer, Baijal, & Pegurri, 2011). Public attitudes towards those infected also vary with the social category of the infected because some high-risk groups, such as MSM and migrants, belong to marginalized populations, who are already stigmatized, even without HIV. As Link and Phelan (2001) noted, stigma is dependent upon economic, political and social power imbalance between those doing the stigmatizing and the stigmatized. It takes power to stigmatize.

Land and Linsk (2013) observed that public attitudes towards those infected with HIV is sometimes based on misconceptions and ignorance about transmission risks. Many people still wrongly believe that HIV is transmitted through casual contacts such as handshakes or the sharing of utensils (Aggarwal et al., 2006; Obermeyer et al., 2011). One participant in the present study noted that his own sibling used to cover the toilet seat with tissues before use, to reduce the perceived risk of contracting HIV. Although the provision of HAART has reduced the risk of adverse consequences such as physical disfigurement and death (Zuch & Lurie, 2012), HIV is still highly stigmatized, in part because it is seen as a 'dirty' disease, and also because it is still feared. Infected individuals with access to HAART have to adhere to a lifelong treatment regime (Stutterheim et al., 2012). Furthermore, the side effects of some anti-HIV medications can cause noticeable changes in the appearance of some individuals undergoing treatment, exposing them to stigmatization. Anti-HIV medications as used here refers to HAART. One side-effect reported by some of the present participants is lipodystrophy, disfiguring of the body due to irregular body fat redistribution (Henkel et al., 2008) which can be visible, depending upon where it occurs. Affected individuals can also suffer from internalised and anticipated stigma, possibly projecting their own attitude towards

their body changes onto those perceived to be stigmatizing, who may in fact be unaware of the infection. One female participant was deeply concerned about losing her feminine figure because of lipodystrophy, saying that without her figure she had lost her womanhood. Reactions to such bodily changes may add to other multiple sources of stigmatization, discussed in the next section.

1.5.3 Layered stigmatization

By 2010 when the fieldwork for the present study began, Black Africans, together with MSM and injecting drug users, were the three populations most at risk of contracting HIV in the UK (HPA, 2012b) as discussed in the previous section. The negative attitudes directed at these populations were reinforced by HIV stigmatization directed at those seen to 'carry' a risk factor and, more particularly, at those who were known to have actually been infected.

Thus, the participants faced layered stigma (Obermeyer, 2008), defined as multiple interrelated stigmatizing attitudes that mutually reinforce each other and act to further marginalize a vulnerable population (Henkel et al., 2008). Thus, Black Africans living in the UK face multiple forms of stigmatization because of HIV, being immigrants, low socioeconomic status, African ethnicity and skin colour (Anderson, 2008a; Rudolph et al., 2012). The study population were often stigmatized in the UK as health tourists taking advantage of free healthcare (NAT, 2008). Sinha (2009) observed that attitudes towards asylum seekers, in particular, as a burden on services and a vector for HIV transmission, has resulted in them being discouraged from accessing health services. As discussed above, many Black Africans test late for HIV. The responses of those affected by layered stigmatization are discussed in the next section.

1.5.4 Discredited versus discreditable HIV attributes

One of the key drivers of stigma is prejudice, that is, unfounded beliefs directed towards individuals because of factors such as their gender, sexuality, social class, nationality, ethnicity or HIV-positive status (Baral, Karki, & Newell, 2007). When stigmatized individuals accept prejudice directed towards them as true, they are said to have internalised stigma (Hasan et al., 2012; Larkan, 2004; Overstreet et al., 2013). However, internalised stigmatization can only be actualized if the stigmatized attributes are recognisable. Stigmatized individuals can therefore be grouped into the discredited or the discreditable, depending on the concealability of the stigmatized attribute (Fernandes et al., 2011). Discreditable individuals, on the other hand, have non-discernible conditions such as asymptomatic HIV, but can become discredited at any moment, should their condition become known. Asymptomatic HIV-positive individuals such as the present participants could voluntarily disclose their infection, retaining more control over the information about their status, as long as their infection remained concealable. However, the presence of medication and other HIV-related resources in such individuals' environment could betray their HIV status. The risk of exposure was also heightened by the impossibility of guaranteeing that their confidentiality would be maintained by those with whom they had shared information about their HIV status. The findings will show that the perceived discernible signs of infection are interpreted differently in different cultural contexts, because stigma is socially constructed (Bos et al., 2013). Three research participants said that their severe weight loss was identified as an AIDS indicator in their countries of origin, where access to treatment was still limited. The same participants did not report any concerns about what people made of their weight loss in the UK. The next subsection discusses the consequences of HIV stigmatization and responses to it.

1.5.4 The implications of HIV stigma for the participants and their responses to HIV stigmatization

Across different cultures and countries, HIV-positive individuals and their families face a daily reality of possible HIV stigmatization within their families, communities and in public institutions such as healthcare facilities, workplaces, media and government legislation and policies. As outlined above, stigma is multifaceted and damaging. It affects employment, housing and education, among many other aspects of social life; and different people respond to it differently (Carr et al., 2010). Scambler (2009) noted that discredited individuals tend to respond to stigmatization by trying to modify their blemish, whereas the discreditable manage their secret in an attempt to retain control over their hidden attribute. The interplay between the revelation and concealment of HIV status and the desire to retain control over the information regarding their diagnosis formed the core of the present thesis.

According to Ho and Mak (2013), contracting HIV in individualistic societies such as the UK, where there is less communal attachment than in many African settings, is broadly perceived as an individual responsibility. The reputation of the infected individual's family is more likely to remain intact because HIV stigmatization is directed primarily, although by no means entirely, towards the infected individual. However, in the more collective communal cultures common in sub-Saharan Africa, being infected by HIV often brings shame to families (Bos et al., 2013; Ho & Mak, 2013). Ho and Mak (2013) added that the reputation of families in communal cultures may be threatened by disclosure of the infection, making individuals less likely to discuss HIV infection within their families. A participant in the present study said she could not disclose her HIV status to her family members back in Africa if she wanted to uphold the good image of the family in the community. As the present findings will show, some, although not all, HIV-positive people felt guilty and ashamed, due to internalized stigma. Overstreet (2013) argued that some infected individuals resorted to concealment of their HIV status from family members and friends to avoid the risk and consequences of stigmatization on the individual and their family members, such as gossip and social isolation. The present findings will show that the relevant participants were more likely to conceal their HIV status from

the family members living in the collective cultures in Africa, than from those in the UK.

The HIV pandemic is still evolving and some of its consequences, including HIV stigma, are not yet fully understood by the public or by healthcare providers (Cherry, Wadley, & Kamerman, 2012; Hogwood, Campbell, & Butler, 2013). A 2008 survey among HIV clinic attendees in North London found that nearly half of the 403 respondents perceived discrimination by healthcare workers. For example, some reported that they had been denied access to care by dentists or GPs once they had disclosed their status (Jonathan Elford, Ibrahim, Bukutu, & Anderson, 2008). However, Elford et al. noted that their participants were MSM and Black Africans, and HIV stigma was therefore layered upon their other stigmatized attributes, making it difficult to determine whether they were stigmatized for being HIV-positive or because of their other attributes. Quilliam (2010) reported cases of stigmatizing measures in primary health care in the UK, such as some dentists giving appointments at the end of the day, or the word 'HIV' being written in large letters on the front of a patient's GP notes, despite the minimal risk of transmission to healthcare workers or other service users if standard clinical practice guidelines are adhered to (BHIVA, 2012). One of the present research participants said that he was discharged from a London hospital where he had been admitted with kidney complications, after requesting to see an HIV specialist.

With respect to coping with stigmatization, the responses can be entered in two categories, confrontation and selective concealment, both illustrated in the Findings chapters. Some infected individuals become HIV awareness activists and actively confront stigma, trying to normalise HIV (Sengupta et al, 2011) through sharing their own life experiences of living with the disease. Research shows that selective concealment can lead to despair, loneliness, stress, depression, anxiety, loss of self-esteem and self-image (Logie & Gadalla, 2009) because the affected individuals internalize stigma, perceiving themselves in terms of the negative and demeaning perspectives found among the public (Malavé et al., 2013; Overstreet et al., 2013; Tsai et al., 2013). Selective concealment also gives rise to other risks, such as exposure and isolation from wider social networks (Rotheram-Borus et al., 2012).

In this section, the concept of stigmatization has been introduced and discussed in relation to the particular circumstances of HIV-positive Black African migrants living in the UK, with particular reference to multiple stigma, cultural differences in the extent to which individuals and families are stereotyped, and variable responses to stigmatization. These themes will be drawn on in the Findings chapters. The next section reviews the literature on the concept of migration.

1.6 Migration

In order to provide a historical context of the present study population as a marginalized and stigmatized group, this section defines migration and outlines the history of migration by Black Africans into the UK. It also considers public perceptions about immigrants and the responses of immigrants to negative stereotyping. The link between immigration and access to and the use of healthcare is discussed where relevant. The material which follows is linked to that presented in previous sections, since immigration is intertwined with family, HIV and stigma. The present study population therefore belonged to a racial and ethnic minority sub-population, generally of poor socioeconomic standing in the UK (Anderson, 2008b; Doyal, Anderson, & Papparini, 2009; F. Thomas, Aggleton, & Anderson, 2010), and subject to racial prejudice and negative attitudes towards Sub-Saharan Africans. Migration as considered in this thesis refers to the movement of individuals from sub-Saharan Africa to the UK, for various reasons and for indefinite intended stay in the UK.

Although not the main focus of the present study, understanding the historical background of Black Africans as an ethnic minority group provides the context for the widespread social inequalities and multiple stigmatization faced by those who are also HIV-positive. In the modern era, recruitment to the labour force from former British colonies in the period following the Second World War led to the build-up of Black and other minority ethnic (BME) immigrants (Boyle, Halfacree, & Robinson, 1998), who have become the symbol of international migration in the UK (Finney & Simpson, 2009; Kern, 2013). However, Black Africans as an ethnic group have physically discernible attributes, making them a distinctive symbol of immigration in

the UK and other Northern countries, even though many are actually British nationals born and brought up in the UK. Over the years, continued immigration from the former British colonies has steadily built up the Black African population in the UK.

Boyle et al. (1998) noted that initially, the new immigrants from the Commonwealth had, just like the native British, full rights to permanent settlement and full entitlement to public services such as healthcare. However, unlike their predecessors, some of the more recent immigrants, such as the present study population, do not have the same entitlements, increasing their vulnerability to socioeconomic hardship and stigmatization (F. M. Burns & Fenton, 2006; Ibrahim, Anderson, Bukutu, & Elford, 2008), as discussed above. By 2009, an estimated 799,000 individuals living in England and Wales identified themselves as Black Africans, many of them asylum seekers from Eastern and Southern Africa (ONS, 2011), such as those who took part in the present study. The World Bank estimated that there were 357,615 East-Africans (Burundi, 2678; Kenya, 152,999; Rwanda, 3143; Somalia, 110,326; Tanzania, 34,327; Uganda, 54,122) living in the UK in 2010 (IOM, 2013). However, these data may involve only documented immigrants (Esses et al., 2010) and exclude individuals who have since become British citizens and no longer claim those nationalities.

The presence of immigrants in the UK has led to a variety of public and official perceptions of immigrants in general, and of Black Africans as an ethnic minority group, because immigration in general has influenced all sectors of the British society (Panayi, 1999). Delamothe (2012) noted that the UK had become distinctively anti-immigration compared to other rich nations with higher proportions of foreign-born nationals, a negative attitude fuelled by false assumptions about immigrants. For example, the perception that immigrants in the UK are health tourists (NAT, 2008) had led to policy directives to charge them for healthcare, including HIV treatment, although that particular policy was reversed in 2012 (Department of Health (DH), 2012). Policy headlines such as *Controlling immigration: regulating migrant access to health services in the UK* (Home Office, 2013) highlight the official view of immigrants and are particularly relevant to HIV-positive members of the present study population who rely on the healthcare for

survival. Delamonte (2012) pointed out that such negative public and official attitudes ignore the positive contribution of immigrants to British society, such as that made by the 37% of NHS doctors and 13% of nurses who were foreign-born.

The effects of negative public attitudes towards immigrants are numerous. Brown (2007) argued that this hostility leads to discrimination at the individual and national levels, due to perceived threats to national identity and to the economic, cultural and physical well-being of the host society. Kern (2013) concurred, noting that immigration has created a multicultural British society with associated benefits and challenges. Hjelm et al. (2012) observed that immigration has led to challenges in healthcare because some disease patterns, health beliefs and health-seeking behaviour, as well as the ability to express symptoms or signs of illness and health, vary significantly between different cultures sharing a host country. Unfavourable public attitudes towards immigrants are linked to perceptions of negative social impacts of immigration, such as overcrowding and strain on public services (Migration Watch, 2013), unemployment, crime (British Futures, 2013) and the spread of certain diseases, including HIV (Wohlgemut, Lawes, & Laing, 2012). Concern about these perceived social challenges have contributed to some level of public hostility towards immigrants and to their stigmatization (Kern, 2013), while the benefits of immigration, such as counteracting the problems associated with an ageing society, tend to be overlooked.

Grove and Zwi (2006) observed that the language used to describe immigrants in the public media, such as flood, mass or wave, metaphorically conveys large-scale disaster to the native population. Such metaphors create the idea of immigration overload in the UK (Kern, 2013). Ironically, one of the HIV prevention goals in the UK was to get HIV-positive Black Africans to access healthcare more quickly, because they often test for HIV too late (NICE, 2011), creating an avoidable infection risk for the rest of the population. Delamonte (2012) has pointed out that asylum-seekers have been the focus of huge public debates about immigration but, in 2010 for example, only formed 3% of immigrants. Such misconceptions lead to discrimination and the marginalization of immigrants (Brown et al., 2007; Brown & Zagefka, 2011). Immigration has also been associated with terrorism, a link which reinforces the 'othering' (Crisp, 2003) of immigrants in general, irrespective of their

religious affiliations or political views. In the context of HIV, sensational headlines regarding the prosecution of immigrants for HIV transmission (Daily Mail, 2011) have further fuelled negative attitudes towards Black African immigrants, especially those living with HIV (UNAIDS, 2012a).

Immigrants are likely to face particularly negative public attitudes if they are perceived as economically non-viable individuals and to have unassimilable cultural attributes (Aalberg, Iyengar and Messing, 2012) such as the ethnicity of the present study population. Ironically, for immigrants to effectively contribute to the host society, they need to be fully integrated into the labour market, which does not promote their involvement, as demonstrated by their vulnerability to long-term unemployment and social exclusion (OECD, 2006, 2012). None of the present participants with the right to work in the UK was able to secure a job in their fields of expertise, with some becoming HIV awareness activists not merely because of their keen interest in this issue, but also because their qualifications were not recognised in the UK and they could not secure more lucrative employment.

However, the communication challenges reported by some of the present participants can also be linked to their cultural and social backgrounds. The present study population came from countries with inadequate healthcare systems (Forland et al., 2013) compared to that in the UK. Many were potentially exposed to a variety of diseases and endured traumatic experiences before they ultimately migrated (Pourgourides, 2007). As already noted, their health beliefs and health-seeking behaviour, as well as the language they used to express their illness or health, were bound to differ from what was normal in the British system (Hjelm et al., 2012). The combination of negative attitudes and unfamiliarity with the host culture makes the study population vulnerable to mental health concerns (Pourgourides, 2007) as the findings will illustrate. The experiences or anticipation of stigmatization could in part explain the reluctance by members of the study population to access healthcare (Susham Gupta & Bhugra, 2009) or to discuss their health concerns.

Migrants from poor countries often leave behind families who have high economic expectations of them (Hjelm et al., 2012). Research (Dodds et al., 2008; Hickson et al., 2009) has shown that Black African immigrants living in the UK are often more

concerned about their uncertain immigration status and unemployment than about being HIV-positive, in part because they had family members in their countries of origin waiting for their support. Although being HIV-positive should not impact directly on economic prospects in societies where HAART is readily available, understanding that the condition may still be viewed as a 'death sentence' in Africa (Musheke et al., 2013) may contribute to disclosure reluctance, in part because of the apparent damage which it does to the person's capacity to contribute toward the family finances.

This section has reviewed the impact on immigrants to the UK of stigmatizing attitudes towards them. The generally impoverished socioeconomic backgrounds of the study population, itself a consequence of discrimination, also affected how they perceived themselves and their living circumstances in the UK, as trans-nationals living with HIV. Many members of this population do not have full right to public entitlements, making them socioeconomically vulnerable and dependent upon state support, itself only available to those with regular immigration status. They live with cultural obligations and family expectations in their countries of origin which may contribute to a reluctance to disclose their HIV status to more than a few trusted individuals. The next section reviews the literature on the disclosure and concealment of HIV status.

1.7 HIV status disclosure and concealment

The above sections have reviewed literature on some of the most important contextual issues relevant to living with HIV, namely the current state of the HIV epidemic, family relations, stigma and migration. This section reviews literature on the core category of disclosure versus concealment of HIV status. It defines disclosure and concealment and discusses the social contexts in which both occurred, as individuals attempted to manage who else knew of their diagnosis.

The issue of HIV status disclosure has gained international prominence in recent years because of, firstly, its implications for primary prevention and secondly,

increased concern about the impacts of living with HIV. However, the meaning of the term tends to be taken for granted. A review of recent published studies (e.g. Hightow-Weidman et al., 2013; Madiba, 2013; RoCHAT, Mkwanazi, & Bland., 2013; Winchester et al., 2013) suggests that authors assume that the meaning is obvious. The Oxford Advanced Learners Dictionary (2013) defines disclosure as imparting information that was previously not known. Saiki and Lobo (2011) argue that disclosure involves more than merely revealing information, but carries the implicit connotation that the content is potentially stigmatizing. For this reason, the term 'concealment' rather than 'non-disclosure' will be used in the Findings chapters to convey an active decision not to impart information about HIV-positive status to others who might have been told. Disclosure is multi-contextual and not an 'either/or' concept, because it involves decisions about whom, when, what and how to disclose the news to others (Moses and Tomlinson, 2012; Lee et al., 2013). Disclosure involves sensitive topics, but sensitivities vary between cultures and social groups, as discussed above. Concerns about disclosure therefore vary between different social groups. According to Saiki and Lobo (2011), disclosure carries an implicit request for care arising from revealing significant personal information, which exposes the bearer to the risks of negative judgement and rejection. Hence, disclosure invokes trust.

Disclosure is a common theme across many aspects of social life, but particularly in relation to stigmatized health conditions and ill health; and disclosure decisions can have far-reaching consequences for the individual and their social relationships. Studies have shown the crucial role of disclosure in the personal management of many contemporary societal challenges such as HIV and AIDS (Armendinger, 2009; Fitzgerald, Collumbien, & Hosegood, 2010), sexuality (Corneli et al., 2009), child abuse and neglect (Schaeffer, Leventhal, & Asnes, 2011), cancer (Henderson et al., 2002), drug and alcohol addiction (Mallow, 1998; Lunze et al., 2013) and mental illness (Craig, Jajua, & Warfa, 2009; McDonald, 2008; Ueno & Kamibepu, 2012; Willerton, Dankoski, & Sevilla Martir, 2008). All these social issues involve sharing deeply-held, sensitive personal information, which is often stigmatized, with significant social and health implications for both the bearer of the condition and their social networks. According to Heeren (2011), disclosure is therefore a

fundamental part of the social world, deeply entrenched in society, as illustrated by the popularity of intimate TV chat shows and the assumptions underpinning mental health and psychotherapeutic intervention.

Saiki and Lobo (2011) argue that, rather than being merely the imparting of information, for disclosure to occur the previously unknown content must be of significance to the individual's self-concept. The individual must also perceive the need for help to cope with their situation and be ready to face unknown outcomes. For instance, one participant in the present research disclosed his HIV status to his sister and brother, expecting both their support. However, the brother subsequently rejected him. During disclosure, the individual making the disclosure shares the information through communication or behaviour that can elicit a response from their confidant. Disclosure thus weakens an individual's ability to maintain an appearance of normalcy (Saiki & Lobo, 2011), which it is often designed to restore (Lakoff & Kovecses, 1987). Disclosure and the processes arising from its consequences unfold over varying time-frames, sometimes lengthy (Georges, 1995; Ssali et al., 2010; Hogwood et al., 2013; Lee et al., 2013). For instance, Lee (2013) assessed the barriers to and motivators of disclosure in Thailand and found that infected individuals were more likely to disclose their status the longer they had lived with HIV. Disclosure involves an ongoing, individually variable process of self-management (Lee et al., 2013), as the findings of the present study will illustrate. Saiki and Lobo (2011) pointed out that disclosure of significant health information can initially be tentative. Some of the present research participants referred to "testing the waters" by revealing hints about their condition in order to gauge potential reactions.

Beals & Peplau (2006) concluded that disclosure of a stigmatized status can have both immediate and long-term impacts on an individual's social relationships. Disclosure of HIV-positive status can open up access to support groups and new friendships (Kaaya et al., 2013; Wouters et al., 2009), but also introduce risks of social rejection, prejudice and even violence (Beals & Peplau, 2006). Disclosure creates uncertainty about potential responses, since the person who discloses sensitive personal information cannot predict the meanings that the recipients will give to it (Alegriá, 2010; McDonald, 2008; Sheon & Lee, 2009). As the present

findings will illustrate, disclosure can also lead to risks such as disrupted interpersonal relationships, irreversible family role changes and discrimination (Gramling, 2000; McDermott, 2006).

Given these challenges, disclosure of HIV infection remains an individual and public health challenge globally (Heeren, 2011), despite recent advances in HIV treatment and care. Moffett & Ross (2011) noted that one of the primary concerns for many newly diagnosed HIV-positive individuals is with whom they should share the information. Although not a legal requirement in the UK, disclosure to sexual partners is important in preventing onward transmission of diagnosed HIV, an act which is liable to prosecution (Grant & Betteridge, 2011; The Crown Prosecution Services, 2009). With respect to HIV status disclosure, Obermeyer et al. (2011) reviewed all the published literature between 1997 and 2008 and of all 231 peer-reviewed publications included in the review, 157 were from richer nations, mainly the United States. The remaining 76 papers were from lower income countries, 49 of which were from Sub-Saharan Africa. Ninety-eight of the reviewed papers concerned heterosexuals of both sexes, with 49 focused on women. Of the 35 studies focusing on MSM, 31 were done in the USA. More than half of the studies, 134 of the 231, were quantitative surveys, whereas 74 were qualitative studies, and a further 11 used mixed methods, combining surveys with qualitative methods. Only seven of the 231 studies included in the review were from the UK, and none of these focused on heterosexual men. Overall, only eight studies reviewed provided data on heterosexual men, six of them conducted in the USA, one in Asia and another in Latin America. The population whose needs were explored in the present study, namely Black African immigrant men living with HIV in the UK, have received little research attention but represent a group with a relatively high prevalence of the disease.

Obermeyer et al. (2011) concluded from their review that, as the present findings will also illustrate, the majority of people living with diagnosed HIV disclose their condition only selectively. At the same time, few manage to keep their HIV-positive status entirely secret. The need for and perceived likelihood of receiving social support determine an HIV-positive individuals' willingness to reveal their condition.

Disclosure recipients are more likely to be supportive of the HIV-positive person when they anticipate less demand on their personal resources. The review also found that gendered roles are associated with disclosure decisions and responses. Mothers and sisters were more likely than fathers and brothers to be disclosure recipients. The research shows that fear of stigmatization, perhaps particularly strong among ethnic minority groups, makes concealment of HIV-positive status more likely. For instance, Black African Americans are less likely than European Americans to disclose their HIV-positive status (Emler, 2006). The reviewed research suggests that disclosure of HIV-positive status is a gradual process that is more likely to occur the longer one lives with diagnosed HIV.

Most of the quantitative studies reviewed by Obermeyer et al. reported disclosure frequencies, depending on the type of information passed on and the recipients of the information. For instance, the review found that lower socioeconomic status reduced rates of disclosure among women in Tanzania, male sex workers in Dominican and Canadian female sex workers. Research also shows that HIV-positive individuals are more likely to disclose their status to their family members than to friends. Some studies in India (P. Taraphdar et al., 2011; Pranita Taraphdar, Dasgupta, & Saha, 2007) have reported higher disclosure rates by literate participants compared to illiterate ones. Obermeyer et al. noted that the qualitative studies they reviewed focused on the meaning and dimensions of disclosure. The review identified considerable concern about discrimination against those whose HIV-positive status became known. Informants felt that they were likely to face negative consequences such as disruption to family life, violence, divorce and rejection by family members and friends. But the researchers noted the difficulty in drawing cause-effect conclusions about HIV status revelation and negative consequences because of the lack of baseline data on such negative experiences. Many HIV-positive individuals are also vulnerable to discrimination and stigmatization because they belong to disadvantaged communities such as marginalized immigrants, MSM and injecting drug users (Jonathan Elford, 2009). As outlined above, the review identified limited UK-based research into disclosure of HIV-positive status. Furthermore, none of the studies reviewed provided data on

the perspectives of the present study population, a gap which the present study attempted to fill.

Although concealment is often adopted in an attempt to avoid risks such as rejection, information spread to third parties and distress to others, it can also create new risks for those concealing their status. Lee et al. (2013) noted that the risk of people living with HIV being depressed is threefold if they conceal their infection from significant others. Concealment can provide the backdrop for behaviours which result in increased risk of HIV transmission such as unprotected sex (Tsai et al., 2013). But when an individual discloses their HIV-positive diagnosis, the information is taken out of their control and they become more likely to be exposed. However, if the infected person decides to conceal their infection, people may still find out through other cues, such as the presence of anti-HIV medications in the house or the infected individual being spotted at an HIV clinic. These issues will be discussed in Chapter 4, on concealment of HIV-positive status.

HIV status disclosure is an important aspect of living with the condition and fundamental to the continuum of HIV care (WHO, 2011). Unlike with most other sensitive or stigmatized conditions such as cancer or gambling addiction, HIV status involves both private and public interests. Obermeyer et al. (2011) argued that although HIV-positive individuals have a right to privacy about their infection, the public also have a right to know that a person is infected because HIV is a debilitating infectious disease (Fair & Albright, 2012). However, recent evidence (Kalichman, 2013) has shown that the risk of transmission is minimal for those on successful therapy. Nevertheless, HIV still retains the aura of a condition which makes those infected a risk to others whilst, at the same time, is linked to confidentiality and privacy as human rights issues (Obermeyer et al., 2011).

This subsection has defined disclosure and discussed the distinctiveness of HIV status disclosure. The next subsection focuses on the relational contexts of HIV status disclosure and concealment with particular reference to the present study population.

1.7.1 Relational contexts for disclosure and concealment of HIV-positive status

HIV-positive status disclosure, concealment and exposure occur in different cultural and relational contexts, depending on the personal circumstances of the HIV-positive individual (Simoni & Pantalone, 2004; Greef et al., 2008). In the case of the present study population, disclosure or concealment decisions were influenced by the cultures of their countries of origin, as well as by a diverse British culture. As Gaskin et al. (2011) noted, HIV status disclosure is a selective process that involves undertaking an informal risk-benefit analysis before deciding whether to divulge this information. Mayfield et al. (2008) noted that the choices people make regarding disclosure leads to three common disclosure pathways: disclosure to everyone; selective disclosure to some people; and total concealment. The present participants mainly adopted the selective disclosure pathway, although four of them had transitioned to public disclosure as already discussed.

Quite commonly, HIV-positive individuals first disclose their infection to one trusted person, with whom the news of diagnosis may remain for some time, before being shared with other people, sometimes with the support of that primary recipient of the information (Maman, van Rooyen, & Groves, 2013). Family members are most likely to be the first disclosure recipients (Gaskins et al., 2011; Mitchell & Knowlton, 2009; Wilson et al., 2013). As the present findings will illustrate, even among family members, some individuals are more likely than others to be told about the positive diagnosis. In a study involving rural African American men, Gaskins et al. (2011) concluded that mothers were the most likely to be confided in, followed by sisters because they could be trusted with the information and relied upon for future support. Similarly, Kalichman et al. (2003) found that mothers and sisters were perceived to be more supportive, and were more frequently disclosed to, than were fathers and brothers. However, Dageid et al. (2012) found that some HIV-positive individuals do not disclose their infection to parents, in order to protect them from distress. Their respondents preferred to disclose to siblings than to parents, mainly

because the latter tended to provide material as well as emotional support to the infected individual and their families.

Other studies in different settings (Davidson et al., 2012; Lee et al., 2013; Medley et al., 2009; Obermeyer et al., 2011; Wong et al., 2009) also reported that women are generally more likely to be the disclosure recipients and also that, among HIV-positive individuals, women are more likely than men to reveal their infection, as the present findings will further illustrate. However, Deribe et al. (2009) explored gender variation in disclosure in Ethiopia and found no significant difference in disclosure between men and women, arguing that the difference may lie in the disclosure motivators or barriers. They concluded that male-dependent women were reluctant to disclose their infection in order to retain support, whereas men avoided disclosure to their sexual partners to avoid gossip and queries about their sexual past.

Contextual differences such as the high degree of dependency of women living in Ethiopia may explain the differences between the findings of such studies. As will be seen in Chapter 6 on disclosure, the female participants in the present study, whose socioeconomic and family roles were relatively independent who were in quite loose family structures, were more likely to disclose their HIV-positive status than men. The literature also shows that HIV-positive individuals tend to reveal their infection to sexual partners to varying degrees in different social contexts. Mayfield Arnold et al. (2008) reported that the rate of disclosure to heterosexual adult partners was lower in resource-limited settings, where some people may be involved in sexual encounters without disclosure in order to protect a fragile societal position. Fear of negative social outcomes such as exclusion, blame, stigma, discrimination and violence, leads to concealment of HIV infection from sexual partners, which in turn affects management of HIV, including adherence to medication (Maman et al., 2013). However, a study by Dageid et al. (2012) on disclosure among heterosexual Black South African men found that the men preferred to disclose to their sexual partners and siblings, rather than their parents and the community. Concealment of the infection from the wider community was designed to reduce the risk of stigmatization, as already discussed. A similar preference for disclosing to sexual partners has been found among African-American male urban clinic attendees (Shacham et al., 2012) and Zimbabwean women (Patel et al., 2012). Research

shows that the higher rates of disclosure among sexual partners arises in part from concern about infection avoidance (Kouanda et al., 2012; Ssali et al., 2010; Suzan-Monti et al., 2011), particularly in relation to awareness of the criminalization of HIV transmission (Horvath, Weinmeyer, & Rosser, 2010; Mugweni, Pearson, & Omar, 2012; UNAIDS, 2012a). A longitudinal qualitative study involving HIV-positive South Africans found that disclosure to sexual partners was also meant to encourage the partners to test for HIV (Maman et al., 2013), a finding that will be supported by the present study.

However, some researchers (Przybyla et al., 2012; Vu et al., 2012; Wei et al., 2012) have concluded that disclosure to sexual partners is more likely among long-term rather than casual sexual partners, where concealment, often together with HIV risk factors such as unprotected sex, are common (Benotsch et al., 2012; Edwards-Jackson et al., 2012). A study on disclosure in Thailand found that the fear of rejection and the risk of isolation led to concealment of HIV status to current or new sexual partners. Disclosure was more frequent among steady partners who were mostly HIV-positive (Lee et al., 2013). As also found in the present study, Przybyla et al. (2012) reported a greater likelihood of concealment among people who perceived a higher risk of stigmatization, irrespective of their relationship characteristics. There is limited data on concealment from long-term sexual partners. Studies in this area have focused on barriers to disclosure such as alcohol (Lunze et al., 2013) or female dependence on women (Jasseron et al., 2013). McKay & Mutchler (2011) found that men with primary female partners were reluctant to disclose their infection to them, in order to avoid questions about their fidelity.

In addition to family members, research has also shown that HIV-positive individuals tend to disclose their infection to friends, who can be another important potential source of social support (Grant et al., 2013; Lee et al., 2013). Grant et al. (2013) suggested that disclosure to friends can also spell the end of the friendship, depending on how the friends react to the news. Kalichman et al. (2003) reported that some individuals were more likely to reveal their infection to friends than to family members because they perceive the former to be more supportive. However, Obermeyer et al. (2011) reviewed literature on the disclosure of HIV status and

concluded that disclosure to relatives appeared to be generally more likely than disclosure to friends. Other studies have found that the likelihood of disclosure to friends depends on the level of friendship (Mayfield Arnold et al., 2008; Obermeyer et al., 2011) and the friend's HIV status (Przybyla et al., 2012; Salami et al., 2011). HIV-positive friends and close friends are more likely to be confided in. Overall, the variability found in disclosure patterns seems to reflect differences in social context, an issue explored in some depth through qualitative analysis in the present thesis.

Research also shows that HIV-positive individuals with children tend to disclose their positive status to some or all of their children, depending on their individual circumstances (Krauss et al., 2013; Madiba, 2013; Qiao et al., 2013; Rochat, Mkwanazi, & Bland, 2013; Saunders, 2012). Qiao et al. (2013) noted that disclosure of HIV status to children is important for the wellbeing of the parents and the children, for parenting and custody plans and family relationships. However, parental HIV status disclosure carries with it associations with stigmatized HIV risk factors, such as having had multiple sexual partners. Feelings of shame may therefore influence parental decisions to conceal their infection from their children (Letteney, Krauss, & Kaplan, 2012). However, as the present findings will show, some parents may be willing to disclose their status, or the children's own status, but feel they lack the skills to do so.

Knowledge about a parents' illness can be stressful to children. On the other hand, Ueno and Kamibeppu (2012) have argued that a lack of information regarding parental illness can cause anxiety and confusion among affected children, who tend to make meaning of their parents' conditions based on their own limited knowledge, when no-one is willing to tell them what is going on in the family. A study into the impact of parental disclosure of positive sero-status on adolescent children found that behaviour problems could result (Lee, Lester, & Rotheram-Borus, 2002). Hough (2002) concluded that finding out that their mother, as opposed to their father, was HIV-positive, was more likely to increase the risk of their uninfected children developing psychosocial problems. Some children were found to experience distress about their mother's HIV status being disclosed (Murphy et al., 2004). However, most research has focused on the negative impacts of HIV-positive status disclosure.

A study of adolescents found that under normal circumstances, children who became carers of their HIV-positive mothers, after disclosure, were more likely to develop improved autonomy in their adolescence than were peers with uninfected parents, and were therefore less likely to be involved in alcohol and drug use (Murphy et al. 2008). Two female participants in the present study said that their children were very supportive of them and lived independently with full knowledge of their mother's illness. But Chaodir et al. (2011) noted that disclosure to children is a daunting psychological challenge for parents because, of the HIV-related stigma. HIV-positive adults also experience high rates of depression, anxiety and other psychiatric symptoms (Letteney et al., 2012), which on their own are difficult to explain to children, while having negative impacts on the parenting abilities of those affected. Fekete et al. (2009) found that, as with adults, boys were less likely than girls to be told about HIV in the family. Kraus et al. (2013) argue that disclosure of parental HIV-positive status to children is challenging because it requires more than a one-off action. It involves further discussions as the challenges of HIV in the family are worked through, because the children are bound to worry about parental prognosis as well as their own future.

The attitudes of HIV-positive individuals towards disclosure to children vary, especially regarding the age at which children should be told about HIV in the family (Calabrese et al., 2012; Heeren et al., 2012; Zhou et al., 2012). Disclosure of parental HIV to children generally becomes more likely as children get older (Lee et al., 2013; Qiao et al., 2012, 2013). High rates of disclosure to teenage children have been reported (Heeren, 2011; Heeren et al., 2012; Krauss et al., 2013). Age-appropriate disclosure, even to children aged six years and below, has been advocated (De Baets et al., 2008; Krauss et al., 2013). De-Baetes et al. (2008) concluded that parents who disclosed their HIV status to their children tend to disclose more fully to adolescent than to younger children. The decisions of some parents to conceal their infection from their children are influenced by media portrayals of HIV (Madiba, 2013) and fear of death, stigmatization and discrimination (Madiba, 2013; Nam et al., 2009; Young et al., 2013; Zhou et al., 2012).

The HIV-positive status of children also raises disclosure issues. According to Heeren et al. (2012), most research into disclosure to HIV-positive children and

young people has focused on the need for, and the barriers to, such disclosure, rather than on the skills necessary for the parents to disclose to infected children. Across different settings, including the UK, there are no standard guidelines for handling disclosure to children. Letteney et al. (2012) noted a particular scarcity of studies into the experiences of fathers on disclosure to their children, a gap the present study attempts to fill. Research suggests, not surprisingly, that attitudes towards disclosure to children are affected by wider social contexts in similar ways to those found for adults. In resource-limited settings such as sub-Saharan Africa which has the most affected children, HIV is still synonymous with death, an attitude carried over to the UK by immigrant Black Africans (Calin et al., 2007). Parents may therefore delay disclosure of parental HIV status to children (Madiba, 2013) in an attempt to avoid them experiencing stress about their prognosis. A cross-sectional study involving 172 parents of HIV-positive school-age children in Ethiopia found that only 16.3% of the children knew about their own diagnosis (Abebe & Teferra, 2012). Some parents also fear that the children might not keep secret the parents' HIV status (Nam et al., 2009), and might thus expose the entire family to stigmatization, isolation and discrimination (Madiba, 2013; Qiao et al., 2013). However, the present findings will illustrate that some children can maintain confidentiality regarding parental HIV status. According to Heeren et al. (2012), some parents avoid disclosure to their children because they feel less than competent to do so (Heeren et al., 2012). Such parents rely on support from HIV support service providers (Lee et al., 2013; Madiba, 2013), as the present findings will further show.

1.8 Summary

This chapter has reviewed the relevant published literature on the key issues affecting communication about HIV-positive status in the context of the present study population. HIV continues to be a major public health concern with considerable consequences for the infected individuals and their families, despite biomedical advances. Immigrant populations such as the present participants face multiple stigma which create complex challenges in their daily lives. The biggest challenge to the present study population was the 'othering' syndrome which affected their acculturation by creating a divide between them and the natives in all social aspects of their lives, leading to stigmatization and discrimination directed towards them as a minority. Another key issue that emerged from the literature review is that the impact of HIV on families is under-researched, particularly in the context of immigrant Black Africans, most notably men, living in the UK. Consequently, the strategies for handling communication about positive sero-status within such families are not well-understood, limiting the capacity of practitioners and policymakers to support families most effectively. The next chapter discusses the methodology used to guide the present study, its theoretical underpinnings and the methods used to conduct the study.

CHAPTER TWO

METHODOLOGY

CHAPTER TWO.

METHODOLOGY

2.1 Introduction

The previous chapter reviewed the extant research literature most relevant to the present study. The purpose of the study was to provide insights into the experiences of HIV-positive immigrant men from East Africa and their families, themselves a culturally diverse category of Black Africans, living in the UK. The study aimed to explore the perspectives of the participants on what it means to live with HIV, including their views on access to and the quality of HIV-related services; and how such services might be improved. This study population form the heterosexual group most affected by HIV in the UK.

This chapter discusses how the chosen methodology and theoretical framework (grounded theory and symbolic interactionism) guided the study design, and reviews the approach taken to sampling, data collection and analysis. The first section discusses symbolic interactionism, a dialectical approach to the relationship between the individual and the society. The second section justifies the choice of a grounded theory methodology to explore complex sexual health issues in a multicultural context. The third and longest section of this chapter discusses the specific methods used for sampling, data collection and analysis, along with the ethical considerations that guided the study. The researcher used in-depth interviews to gather the perspectives of the participants on the meanings they made of family life with diagnosed HIV. The fourth and final section presents the researcher's approach to ensuring rigour.

2.2 Theoretical framework

This section discusses symbolic interactionism as the theoretical underpinning of the present study. Symbolic interactionism was developed in the early part of the twentieth century in the USA, in a cultural context which was much less diverse than those found today in many urban environments, not least that of London and other British cities. Nevertheless, this dialectical approach to the relationship between the individual and society can be readily applied in multicultural contexts, and was considered most appropriate for the exploration of the participants' perspectives on and responses to HIV arising from their meaningful social interactions. In terms of ontology, symbolic interactionism is predicated on the assumption that there are individual and societal interpretive processes which exist independently of the researchers. Epistemologically, symbolic interactionists tend to assume that researchers can in principle discover such meanings. By applying symbolic interactionism, this researcher therefore tried as much as possible to explore the respondents' reality of living with HIV. These ontological and epistemological issues will be discussed further in the following section on grounded theory methodology.

The discussions below will focus on Blumer's (1990) more recent rendition of symbolic interactionism. The more quantitative Iowa school version (Kuhn, 1964) of symbolic interactionism will not be discussed further. Using illustrative examples drawn from the research data, the material which follows discusses the ways in which the key principles of symbolic interactionism guided the study.

According to Blumer (1969), symbolic interactionism is a theory which accounts for human action in terms of a dialectic process involving interplays between the creative self and the society in which the individual lives. Thus, people are born into pre-existing societies, but also change their social worlds, however minutely, through the cumulative impact of their individual meaningful choices. For instance, four of the present participants decided that the best way to deal with HIV stigma was not to conceal their HIV status but to try to change the stigmatizing attitudes towards HIV. Individuals and social groups actively interpret their cultures and understanding the social world necessitates trying to discover the interpretive

frameworks of its human inhabitants, particularly in relation to the inferred underpinning presuppositions. People's environments thus change over time in response to countless individual interpretive decisions, whilst at the same time individuals respond to their environment. For instance, children are born into a language as a cultural symbol of a social fact, but as they grow, they interpret the language in their own distinctive ways, influenced by their environment. A child is thus influenced by the language they are born into, but they also influence the language, as they make meaning of their environment as independent users of the language in their daily social interactions.

To act symbolically, individuals imagine how others perceive them and mentally construct the responses of others to situations they face, such as living with diagnosed HIV. For instance, most of the present research participants revealed their HIV-positive status only selectively to those from whom they anticipated supportive responses. Mead (1934), a key figure in the development of symbolic interactionism, summed up these active, anticipatory processes through the concepts of the self and the generalised other, or the 'I' and 'me'. Mead noted that the human ability to role play enables people to imaginatively see themselves as objects in the eyes of others, as if viewing themselves in a metaphorical mirror. The one looking at the mirror is the 'I', whereas the one staring back from the mirror is the 'me', seen through an individual's active interpretation of how they are viewed by others, and not merely an optical reflection of the 'I'. The 'me' enables the 'I' to describe the 'me' based on how they think that significant others, for example parents, siblings or friends, would view them, a process which requires active interpretive work (Holt, 2011). The 'I' represents the actively interpreting mind of individuals who put their own personal interpretive stamps on the symbolic accounts of themselves which they receive from their social environment. In multicultural societies, this process entails the management of often conflicting meanings, for example, different understandings about the meaning of living with HIV.

The present research participants managed communication about their HIV status within a complex cultural background that was in constant interaction with yet another complex multicultural host society. Symbolic interactionism therefore provided a means of understanding how the participants reflected on what it meant

to live with diagnosed HIV or be part of a family where at least one adult member was HIV-positive. Symbolic interactionism provided a lens through which to explore what it meant for other family members, friends and social contacts to live or interact with the HIV-positive participants or their partners.

The researcher recognized that symbolic interactionism is just one of the many alternative theoretical frameworks that could be used to make meaning of the participant's problematic. Other frameworks, such as social phenomenology, ethnomethodology or interpretive phenomenological analysis (IPA) are also concerned with social reality based on people's subjective experiences. However, as Aldiabat and Novenec (2011) noted, there is a strong historical relationship between symbolic interactionism and grounded theory, as well as compatibility in their goals. In particular, as discussed below, the key grounded theory tenet of theoretical sampling fits well with the symbolic interactionist approach to socially organized but actively created meanings. Blumer (1969, p. 48) noted that symbolic interactionism is a means of discovering the nature of the social world out there waiting "to be dug out by a direct, careful, and probing examination of that world".

2.2.1 The key premises of symbolic interactionism

This subsection discusses the key premises of symbolic interactionism as presented by Blumer (1969), in order to highlight their relevance to the present study. As already discussed, symbolic interactionism provided a theoretical framework for gaining understanding of what it meant for the study population to live with diagnosed HIV. This researcher applied Blumer's three "simple premises" (Blumer, 1969, p. 2) of symbolic interactionism, outlined below, to understand what it meant for the participants to live with HIV.

- a) Human beings act toward things on the basis of the meanings they ascribe to those things.
- b) The meaning of such things is derived from, or arises out of, the social interaction that one has with others and the society.

- c) These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he/she encounters.

The present research participants lived in a society in which HIV is now broadly considered to be a manageable chronic illness (Sagar, 2013), although it remains stigmatized. In their native countries, HIV was still often perceived as a death sentence because of inadequate provision of treatment. Being immigrants, some of the participants faced numerous other socioeconomic issues, such as uncertain immigration status and personal cultural demands, such as the expectation to provide economic support to relatives in their native countries. Because they faced so many other serious problems, HIV was not the most pressing worry for some of the participants. Such individuals were concerned about other issues, such as their immigration status, which was vital for their long term stay in the UK. As Blumer (1990) argued, meanings are not intrinsic, but rather rest in linguistic and social meanings ascribed in particular social contexts.

The following paragraphs discuss the application of each of the three tenets of symbolic interactionism to the complex circumstances outlined above, beginning with the first premise, which asserts that human beings act towards things based on the meanings that things (other human beings, physical objects in the environment, social institutions) have for them. Blumer argued that, although few scholars would dispute that human beings act towards things based on the meanings they have for them, social scientists (at the time he was writing, positivist accounts still dominated the social sciences) had tended to ignore this principle and treat human behaviour as a product of causative factors. The meanings people made of things were therefore ignored in favour of attempting to discover external causative factors for their behaviour (Blumer, 1969). Valsiner (2012, p. 3) has argued that mainstream psychology is still largely culture-blind and suffers from a "self-generated" image of being an objective science which works against understanding "deeply subjective and culturally organized phenomena". Blumer therefore stressed the importance of meaning-making in the way people perceived themselves, their surroundings, the institutions and the manner in which they acted towards all these things. Thus different meanings can be attached to the same social action. For example, one

HIV-positive participant described what he believed was a deliberate exposure of his HIV status by his partner in London to his partner back in Africa. As discussed in detail under exposure in Chapter 5, the man believed his partner wanted to sabotage his relationship with his partner in Africa; while the partner, who was also interviewed, believed she acted to protect her husband's partner from contracting HIV from him. The differences between the couple's accounts illustrate how active interpretive processes can render the same phenomenon at one level of meaning completely different at another.

The second premise of symbolic interactionism states that the meanings of 'things' arise out of the social interactions that people have with others. This second premise draws together the influences of a human being's interpretive and interactive capacities. According to Blumer (1969, pp. 4–5), meanings in symbolic interactionism are social products or "creations that are formed in and through the defining activities of people as they interact". For example, views of their infection as a 'dirty' condition undoubtedly influence the ways in which HIV-positive people see themselves, although, as flagged up in the third tenet of symbolic interactionism, discussed below, individuals do not necessarily accept such social specifications of them.

Finally, the third premise of symbolic interactionism asserts that societally shared meanings are modified through an interpretive process used by individuals dealing with the things they encounter. Blumer argued that the third premise is distinctive to symbolic interactionism because it marks out the active role of individual minds (Yun-Hee, 2004). According to Blumer (1969, p. 5), "it is a mistake to think that the use of meaning by a person is but application of the meaning so derived". People thus actively interpret and modify the meanings they share during the individual versus society interactions. For example, the four research participants who had 'come out' about being HIV-positive attempted to use their approach to their condition to shift societal attitudes towards HIV and those infected, drawing on the process identified in Blumer's third tenet. To them, the way to deal with HIV stigma was not to conceal their HIV status or worry about the risk of exposure, but to go out and confront it.

The use of symbolic interactionism in the present study was complemented by the application of grounded theory methodology, as discussed in the next section.

2.3 Methodology

2.3.1 Introduction

This section discusses how the researcher applied grounded theory in the present study. It is divided into five subsections, including this one. The second subsection provides a historical overview of grounded theory in order to contextualise Strauss and Corbin's (1990) version, which was adopted for this study. The third subsection provides a rationale for the use of grounded theory and the fourth subsection reviews how the various tenets of grounded theory were applied. Lastly, the fifth subsection discusses the application of reflexivity and relationality to incorporate the researchers' influence on the study. The research methods used in the study are discussed in a later section of this chapter after wider methodological issues have been considered.

The term methodology is usually used to cover methods in their wider framework of ontology, epistemology and theoretical underpinnings. Corbin and Strauss (2008, p. 1) define methodology as the general approach to investigating a problem or "a way of thinking and studying social phenomena".

The researcher used qualitative principles to produce findings devoid of any "statistical procedures or other means of quantification" (Strauss & Corbin, 1998, p. 10) and because qualitative methods allow the complexities of personal experiences and the social meanings attached to such experiences, sometimes unfamiliar, to be explored. Bergh (2009, p. 3) argued that qualitative approaches address "meanings, concepts, definitions, characteristics, metaphors, symbols and descriptions of things", making them suitable for the present study which explored unfamiliar complex perceptions and subjective meanings the study population made of their life with HIV. Strauss and Corbin (1998, p. 11) argued that qualitative methods are suitable for studies such as the present one that focus on "people's lives, lived experiences, emotions, feelings or behaviours".

2.3.2 The origins and development of grounded theory

This subsection briefly describes the historical background of grounded theory, in order to contextualise Strauss and Corbin's version. Grounded theory was originally developed by Glaser and Strauss (1965, 1967, 1968) as an alternative to the then-dominant positivist approaches (Holt, 2011). The approach was formally launched through the publication of *The Discovery of Grounded Theory* (Glaser & Strauss, 1967). In the book, Glaser and Strauss justified the rigour and relevance of grounded theory to social research by contrasting its methods with logico-deductive empirical approaches which generated theories based on speculation and deduction. Hallberg (2006) noted that by the time grounded theory was proposed, qualitative research was often used to refine quantitative research tools and was perceived by some quantitative researchers as non-systematic and impressionistic (Ong, 2011). Glaser and Strauss argued that sociological theories at the time were too abstract to be applicable to the 'real world'. Grounded theory was intended to create less abstract middle-range theories because "grand theories" were not empirically testable. The focus on theory development and the methodological instructions on how to conduct and evaluate research differentiated grounded theory from other qualitative approaches (Oktay, 2012, p. 4; Strauss & Corbin, 1998). Hallberg (2006) noted that the publication of *The Discovery of Grounded Theory* was a breakthrough for qualitative research (although grounded theory can in principle be used with quantitative and mixed methods) because it introduced systematic procedures into a discipline that was hitherto mainly taught orally. Thus, grounded theory offered a systematic approach to qualitative methodology (Weed, 2009).

According to Bryant and Charmaz (2007), grounded theory was designed to facilitate the creation of coherent theories which were systematically derived from data. Theoretical concepts are built up through an iterative process of progressively shifting back and forth through the data and successively categorizing concepts in more refined ways which derive from research participants' own concerns rather than the researcher's preconceptions. The approach uses iteration of constant concurrent data collection and analysis because it "uses both deductive and

inductive logic in a back and forth process of theory generation [inductive] and theory testing [deductive]" (Oktay, 2012, p. 17; Weed, 2009). Grounded theory also stresses the importance of generating middle-range theory at a substantive or formal level (Yun-Hee, 2004). A substantive theory is one that is generated from a specific social context, whereas formal theory is generalizable across different settings. For instance, a substantive theory about disclosure of HIV status may be relevant to other stigmatized conditions that can be concealed, such as mental illness or epilepsy. The phenomena discovered can be analysed more abstractly in terms of the dialectic approach to meaning developed in symbolic interactionism, discussed above.

Since its inception, the founders of grounded theory have drifted apart through their subsequent publications. Glaser and Strauss and Corbin have developed distinctive variants of the approach (Corbin & Strauss, 2008, 1990; Glaser, 1992, 2001; Strauss & Corbin, 1990, 1998). Urquhart (2013) noted that the publication of Strauss & Corbin's (1990) book reflected a public spat between Glaser and Strauss over the nature of grounded theory. Glaser subsequently criticized Strauss and Corbin's (1990) version for being too structured, and for having departed from allowing theory to emerge naturally from the data. Despite Glaser's criticisms, Strauss and Corbin's version (1990, 1998) has gained global popularity with many researchers across various disciplines (Kathy Charmaz, 2006; Willig, 2013), partly because their structured analytical guidelines are more comprehensible, particularly to novice researchers (Heath & Cowley, 2004). Van Niekerk and Roode (2009) argued that applying Glaserian grounded theory was more challenging for novice researchers, including this one, especially in postgraduate research where students are expected to fit within the overall faculty goals. Adolph et al. (2011, p. 488) added that leading texts on grounded theory, especially those of Glaser, describe the approach "in near mystical terms", with very few practical examples that less experienced researchers could draw from, making it challenging to apply.

Another influential contributor to the development of grounded theory methodology has been Charmaz. She claimed (2006, p. ix) that her "version of grounded theory returns to the classic statements of the past century and re-examines them through a methodological lens of the present century". She noted that the main differences

between her approach and that of Strauss and Corbin involve coding, memo writing and category development. Charmaz (ibid) maintained that Straussian grounded theory focused on the participant's perspectives at the expense of the researcher's experiences, whereas her version recognized the importance of the researcher's experiences. Hall and Callery (2001) observed that, although Strauss and Corbin acknowledged the researcher's impact on research, they did not fully explore the impact of researcher-participant interactions on data. They called for more consideration of the social construction of data. Unlike Glaser and Strauss who tried to discover the concerns of their participants in a classic symbolic interactionist mode, Charmaz's grounded theory emphasizes the influence of the researcher's experience on the data collected. Further, Charmaz's approach to data coding is limited to two steps, initial coding and focused coding, whereas Strauss and Corbin (1990) argue for open, axial and selective data coding processes carried out concurrently, as discussed further in the methods section below. However, Bryant and Charmaz (2007) acknowledged that many grounded theory researchers use their own modified versions of grounded theory, which should be viewed as an approach to methodology rather than as a set of concrete prescriptions for research methods.

Despite the evolution of grounded theory into many variants, Weed (2009) noted that the following core elements, discussed in more detail in a later part of this chapter, remain common to all versions: theoretical sampling, iterative data collection and analysis, theoretical sensitivity, coding, memos, theoretical saturation, and substantive and formal theory. Open, axial and selective coding can also be considered as core elements, although Charmaz' version has merged them into initial coding and focused coding, as outlined above. The next subsection rationalizes the application of grounded theory in the present study.

2.3.3 Rationale for using grounded theory

This subsection offers a rationale for the present researcher's choice and application of Strauss and Corbin's (1990) version of modified grounded theory. The study was concerned with complex and sensitive sexual health issues affecting a diverse and

complex population group, with very limited previous research to draw from, making the grounded theory approach the most appropriate. As Yun-Hee (2004) observed, issues such as those explored in this study could not fit into the positivist paradigm which tests existing theories and explores cause-effect relationships. Grounded theory is best suited for listening to the voices of the affected such as the present participants, immigrants from diverse cultural and other socioeconomic backgrounds, with very diverse life experiences and expectations living in yet another multicultural host society. For instance, the concept of family meant different things to the individual participants, based on their cultural background and their living circumstances in the UK, as discussed in the literature review in Chapter 1. Grounded theory study design enabled the researcher to tap into and understand constructed meanings of life with HIV under such complex socioeconomic circumstances.

Although criticized for being too mechanical (Hall & Callery, 2001), the structured nature of Strauss and Corbin's grounded theory made it easier to comprehend and apply than the Glaserian version. This researcher was also attracted to the flexibility recommended by Strauss and Corbin (1990, 1998), who emphasised that their procedures are not commandments but merely guidelines to be used flexibly. Although Charmaz's (2000, 2006) constructivist version is also structured (Allen, 2010), the researcher found the two-step data coding procedure challenging to apply. Moreover, the researcher shared a social background with some of the participants and wanted to detach his own perspectives as much as possible from the data analyses. At the same time, taking into account the position of Charmaz, he recognized that data collection and analysis inevitably entailed some degree of co-production between himself and his informants.

Grounded theory was used to develop a substantive theory of communication of HIV-positive status and its implications for social relationships and access to support. Communication about HIV-positive status emerged as the core category and was linked to the categories of disclosure, concealment and exposure, as outlined in the Introduction. The theory has the potential to inform the design of HIV-related policies and services involving Black Africans in the UK. Although the study did not generate a formal theory because of its substantive focus, the resultant

theory of communication about HIV-positive status could be applied to other concealable stigmatized conditions, such as mental illness. The following subsection discusses the key features of grounded theory.

2.3.4 The key tenets of grounded theory

This subsection reviews the key tenets of grounded theory and their application in this study. It is organized into four subsections, focusing on: theoretical sampling; cycles of design, data collection and analysis; theoretical sensitivity; and relationality and reflexivity. The coding processes of open, axial and selective coding, another key feature of the variant of grounded theory which was adopted, are discussed in the data analysis section below.

2.3.4.1 Theoretical sampling

Theoretical sampling refers to the ‘sampling’ of concepts designed to identify the issues most relevant to the group being studied (Strauss & Corbin, 1990). The goal is to obtain data that would allow thorough exploration (Oktay, 2012) and refinement of the emerging theoretical concepts (Weed, 2009). Unlike in other sampling approaches, the aim of theoretical sampling is to refine ideas rather than increase the sample size (Kathy Charmaz, 2000). Theoretical sampling refines ideas by grounding the researcher’s focus in the participants’ concerns, rather than professional or academic disciplinary priorities. The initial focus for the present study was to investigate how HIV affected the participants’ lives and how they responded to the issues which concerned them. As data collection progressed, the focus became more specific because analysis showed that a key concern for most research participants was managing disclosure of their positive diagnosis.

The initial interview questions were based on concepts derived from both the literature and the researcher’s professional experience, as suggested by Strauss and Corbin (1990). These starting-points included length of time living with HIV, disclosure, family, other health conditions, immigration status, HIV stigma, and

access to healthcare. These concepts provided an initial focus from which the rest of the study evolved (Strauss & Corbin, 1990) through sampling further, related, concepts and developing categories in repetitive cycles of design, data collection and analysis. The researcher remained open to the possibility of gaining diverse data by using loosely structured interview guides (Appendices 8, 10 and 11) to allow potentially relevant concepts to emerge from the interviews. The interview guides were modified in subsequent interviews in line with the emerging theory. For example, the initial participants were asked 'who they had told about their condition'. The question was reframed to 'who else knew about their HIV status', to include involuntary exposure, which had been identified as a common concern. Through the participants' feedback, the researcher was also able to identify new lines of enquiry. For example, the initial interview guide did not include the type of the participants' accommodation. But after two interviews, it became apparent that this issue was itself problematic for a number of respondents.

After each interview, the researcher transcribed and analysed the data to identify categories and sub-categories which, if significant, could then be incorporated into subsequent interview guides. See appendix 25 for a sample of an interview transcript. The process of developing categories was aided by constant comparison, another important feature of grounded theory. Constant comparison is the basic method used to create theory from empirical data in grounded theory. It involves the researcher constantly comparing data to generate analytical concepts (Hallberg, 2006; Strauss & Corbin, 1990). In the process of comparing cases, differences and similarities become clearer, enabling the researcher to describe intra-category variations and inter-relationships between categories in ways which are based on the data (Oktay, 2012). In the process, some concepts became irrelevant to the emerging theory and were discarded, whereas some were modified or replaced. For instance, it became clear after six interviews that most of the participants were not caring for other people with long-term conditions or old age due to their socioeconomic circumstances in the UK, and this line of enquiry was dropped entirely. During the interviews, the participants' responses led to adjustment of some of the questions. The researcher also probed the respondents to focus on theoretically relevant data, applying "theoretical sampling on site" (Strauss & Corbin,

1990, p. 183). For example, one participant described their general health as not good, because sometimes he 'abused his health'. When probed, the participant clarified that he had alcohol-related problems which affected his adherence to medications. Connections between alcohol abuse and medication adherence were then explored further in subsequent interviews.

All the theoretical sampling processes described above were done concurrently because data collection and analyses were done through a cyclical iterative process, as discussed in the following section.

2.3.4.2 Iterative design, data collection and analysis

Undertaking repeated cycles of design, data collection and analysis is one of the defining features of the grounded theory approach. Such iteration is enhanced by constant comparative analysis, as described above. The researcher first conducted an in-depth face-to-face interview with the analysis of the interview transcript from a single case. He compared the key issues arising from the data, such as multiple health conditions and family support, with relevant literature. The researcher then proceeded to interview the second man and repeated the entire process of data preparation and analysis. The second transcript was compared with the first and with published literature, to help develop the emergent line of enquiry.

This cyclical process went on until theoretical saturation was achieved, when the research area was theoretically exhausted (Weed, 2009). Theoretical saturation refers to a stage during the grounded theory research process when additional data from the field does not add any new dimensions to the properties of the identified category (Glaser & Strauss, 1967). It is the point at which the core category is fully grounded in data and no more concepts emerge from the additional data (Oktay, 2012). The researcher judged that theoretical saturation had been achieved after he had completed 18 interviews involving families and five with workers from community organisations. In addition, he carried out follow-up phone calls to some participants in order to clarify issues that had emerged during the analyses and had

not been sufficiently covered in the interviews. This iterative process was designed to develop theoretical sensitivity, as discussed next.

2.3.4.3 Theoretical sensitivity

Theoretical sensitivity entails developing a deep understanding of the issues which concern those whose lives are being studied. Although theoretical sensitivity can be enhanced by being immersed in literature and related general knowledge surrounding the phenomenon, it can be compromised if knowledge about previous research stands in the way of 'hearing' what the research participants are trying to say (Weed, 2009). Charmaz (2006) maintained that the grounded theory researcher ought to be informed by the literature but should still retain an open mind. Strauss and Corbin (1990), similarly, argued that, although knowledge of the literature is useful, the researcher should remain vigilant to avoid being buried in it at the expense of the participant's perspectives. The present researcher selectively reviewed the literature so as to update his knowledge about emerging categories such as gender relations, communication with children, reticence about HIV and how HIV affects families. The literature was intended to supplement insights gained from working in the HIV sector both in the UK and in Africa, as well as personal experience of living in families living with diagnosed HIV. For instance, the researcher combined knowledge from published literature concerning HIV-positive status disclosure with his own experience of stigma and concealment in order to help him to understand participant's own concerns about disclosure to family members.

The researcher's knowledge about East-African culture contributed to his understanding of what respondents were saying. For example, he was able to contextualise cases of multiple sexual relationships reported by some participants in terms of their membership of polygamous communities in East Africa. To an outsider, Black Africans were 'known' for having multiple sexual partners simultaneously (Dodds et al., 2008; Nyindo, 2005; Shannon et al., 2012). To an insider, the trend was mainly common among the individuals from culturally polygamous communities. The researcher also shared common dialects (Swahili and Luo) with some of the participants. This made it easier for those participants to fully express their views in instances when they felt the meaning would be lost in English translation, as illustrated below.

Robin: *So he came and asked me ... Koyo omaki koso ango?* [Luo – translated to mean you feel cold or what? This expression is used to ask if someone is ill]. *You know, in my brain I think I know what he is asking me.*

(Robin; 45 years old, HIV-positive for 13 years, lives with wife Harmony; 48 years old, HIV-positive for 14 years, and their 3 children. Have 6 children in total, 4 of whom are Harmony's late sister's children)

The above extract illustrates an inquiry into the participants' HIV status by a relative using figurative language to refer to HIV, illustrating an indirect communication about HIV in the participants' families even when it was suspected. An outsider might well perceive the enquiry as innocuous small-talk but the researcher's familiarity with the dialect, and phrases such as cold, slim or wind being used to refer to HIV in their native community, enabled him at times such as this to develop a more nuanced understanding than might have been available to a researcher who did not share the informants' culture.

As Glaser and Strauss (1967) asserted, theoretical sensitivity grows over time through repeated re-reading and constant comparison, which lead to new insights as the researcher masters a large and increasingly focused range of data. The present researcher developed a better understanding of theorizing and was able to identify key concepts, subcategories and categories as the study progressed, unlike at the beginning when identification of key concepts was a challenge. By the end of data analysis, the researcher was able to identify communication about HIV status as the core category around which other major categories of disclosure, concealment and exposure could be located.

2.3.4.4 Incorporating relationality and reflexivity into grounded theory

This subsection discusses relationality and reflexivity as supplements to the version of modified grounded theory developed by Strauss and Corbin (1990). Hall and Callery (2001) argued for the incorporation of relationality and reflexivity into grounded theory in order to account for the impact of participant-researcher

interactions on the generated data. They argued that the original proponents of grounded theory (Corbin & Strauss, 2008; Glaser & Strauss, 1965, 1967, 1968; Glaser, 1978; Strauss & Corbin, 1990) treat interviews and observations as pure reproductions of the participants' reality, ignoring the fact that data is produced through social processes which generate socially constructed knowledge. Hall and Callery noted that, since research data are created by assigning meaning through the social interactions between the researcher and the researched, it is inevitable that the data will be influenced by those interactions.

Hall and Callery (2001) use the term relationality to refer to recognising and attending to a power imbalance between the researcher and the participants. Reflexivity refers to taking into account the effects of researcher-participant interactions on the construction of data. Hall and Callery (2001) argued that acknowledging relationality can help the researcher to minimize the influence on the impact of the power imbalance which arises during the research process. In other words, the researcher should be sensitive to power dimensions during an interview (Al  x & Hammarstr  m, 2008). Charmaz (2006) noted that differences in power dynamics during an interview can affect who guides the interview and the level of trust, thereby affecting the quality of the data. Al  x and Hammarstr  m (2008) pointed out that such power differences are affected by other socially mediated factors such as age, gender, ethnicity, sexuality and education.

As an immigrant who identified with some of the cultural background and immigration experiences of some of the participants, the researcher was aware of the need to remain reflective throughout the study and to manage power relations between himself and the participants. He strove to cultivate mutuality between the researcher and the researched and to acknowledge the researcher's influence on the findings (Kathy Charmaz, 2000). As an insider, the researcher was more readily accepted because of his sensitivity to the participants' culture.

However, being an insider while trying to approach the study with an outsider lens was a challenge. In grounded theory study design, the researcher strives to guide the direction of the interview process in relation to the emerging research focus, whilst enabling the informants to determine what they share. The researcher at

times may have prematurely closed lines of enquiry, by presuming too quickly that he understood what was being said. However, there were instances when the research participants expected the researcher to know what they meant because of their shared background. Other demographic factors such as age, gender, perceived HIV status and the educational level of the researcher also affected how some respondents discussed certain aspects of their lives with HIV. For instance, some of the female participants were reluctant to speak about their sexual history; and some of the participants adopted a parental tone in some of their discussions, due to the lesser age of the researcher. These challenges were identified at the initial stages of the study and corrected, to some extent at least, by probing for clarification, rather than assuming awareness.

It was difficult to achieve complete power balance because the researcher was seen as an expert, armed with aims and objectives to be fulfilled. Although the participants were given the space as experts in their lives with HIV to share their narratives and to feed back on the key findings, it was the role of the researcher to analyse and interpret the data using knowledge about grounded theory procedures. The researcher made key decisions regarding theoretical sampling, study logistics and study termination. It was not possible to involve the participants in all these processes, due to time limitations and the knowledge required to manage some of them. Although Hall and Callery (2001) argued for reciprocity as a means of minimising the power imbalance highlighted above, experience from the present study showed that trying to do so involves a delicate process that can either enhance or completely distort the interview process. In an early interview, the researcher responded to a respondent's query in a way which was intended to banish stigmatization but inadvertently risked imposing his personal interpretive framework on the interviewee.

Harmony: *How do you feel talking to people with HIV?*

Researcher: *I feel empathy, I feel moved, in some instances. But I am not shocked. Because I come from a background where I have nursed people with HIV ... So, I have had HIV around my life for such a long time that it has become part of me ... I am sure you will remember that ... I am not looking*

at you as somebody who is sick and dying, but am looking at you as somebody with a condition that is manageable. And especially in England, when I talk to somebody with HIV, I even have more courage because I know that it is not as bad as elsewhere that me and you know. Yea, that is how I feel. I hope I am not insensitive to somebody like you.

(Harmony; 48 years old, HIV-positive for 13 years, lives with husband Robin; 45 years old, HIV-positive for 14 years, and their 3 children. Have 6 children in total, 4 of whom are her late sister's children)

The researcher's attempt to empathize led him to assert that living with HIV in London was not as bad as it would be elsewhere, a view not necessarily shared by the person whose views he was attempting to uncover. However, this was only the second interview, and the researcher developed a better understanding of the difficulties associated with balancing empathy with open enquiry as he acquired more experience of the interview process.

In response to the challenge of incorporating reflexivity and relationality into the research process, the researcher took measures, discussed in detail in the methods section, to reduce the power imbalance between himself and research participants, and to take into account the impact of researcher-participant interactions. The researcher continuously reflected on his own knowledge and experiences regarding family communication about HIV, to ensure that the participants' concerns remained foregrounded in the analyses. The use of in-depth face-to-face interviews enabled the participants to take control of their narratives as the experts on their life experiences. As mentioned above, the researcher also used member checks to solicit participants' feedback on his interpretations of their perspectives on living with diagnosed HIV. He discussed the interview process and his interpretive coding in detail with his supervisors. The following section focuses on the methods employed in the present study.

2.4 Methods

The previous section discussed the use of modified grounded theory methodology in the present study. This section reviews the specific methods used to collect and analyse data. The section consists of nine sub-sections. The first eight sub-sections cover study design, the theoretical population of interest, sampling, study location, access to and recruitment of participants, ethical considerations, data collection procedures and the methods used for data analysis. The final subsection discusses the criteria for judging the quality of this research.

2.4.1 Overview of study design

As discussed above, this was a grounded theory study underpinned by symbolic interactionism. The overall aim was to generate a theory that would explain what it meant for the participants and their family members to live with diagnosed HIV and how they dealt with the consequences of the condition in their families. The study was designed to use in-depth interviews to gather rich data because the researcher believed that interviews would give the participants an opportunity to fully describe what it meant for them to live in families affected by HIV. To secure a service-provider perspective, a sample of workers from HIV-related service providers were also interviewed to explore their views on what living with HIV meant for the individuals from the theoretical population who accessed their services. A theoretical sampling strategy was adopted, with data collection and analysis undertaken in recurrent cycles so that the direction of enquiry could take into account emergent themes. The issue of HIV-positive status disclosure was identified as a critical one for members of the research population and became the focus of enquiry. A total of 23 respondents were recruited through London-based community organisation involved in HIV support work targeted at Black Africans living in London. They included one HIV-negative man in a sero-discordant relationship and his partner who was HIV-positive, 11 HIV-positive men, five HIV-positive women who were partners of some of the men, and five workers from London-based community organizations offering HIV-related services accessed by Black Africans. Thematic

data analysis was undertaken in three overlapping stages of open, axial and selective coding. Further details about the specific methods outlined in this overview are presented below.

2.4.2 The Theoretical Population

The study was informed by HIV-positive immigrant Black African men in heterosexual relationships, many of them living with dependent children and their wives or partners. The men, subsequently referred to as the key contact persons (KCPs), were individuals who had been brought up in East Africa and migrated to the UK as adults (aged 18 years or older) at least one year prior to the study, and who wanted to remain in the UK indefinitely. The study specification did not require that their wives or partners to also be immigrants from East Africa. However, the final sample of men and their partners were all East-African immigrants. As outlined above, workers from the collaborating agencies, who did not have to be Africans themselves, were also recruited and interviewed.

2.4.3 Sampling

The initial sample was of KCPs, selected on the basis of the inclusion criteria and having responded to the invitation to consider taking part in the study (see below). The researcher then attempted to recruit a UK partner of the man who had been interviewed. In cases where the partners of the initial KCPs were not accessible, the researcher proceeded to sample other KCPs, hoping to gain access to their partner. Overall, 11 KCPs, five nominated partners, one HIV-positive female and her nominated HIV-negative partner were included in the study, making a total of 18 participants. All the families interviewed were composed of the KCP, the partner and children, who were not interviewed. All of the 18 participants indicated that they were not living with extended family members at the time of the study. Apart from one sero-discordant woman recruited towards the end of the study, the researcher did not actively seek partners on the basis of their HIV status. The wives of the only two

men who were in sero-discordant relationships, where only the man was known to be HIV-positive, did not take part in the study. Towards the end of the study, it was decided to attempt to recruit sero-discordant couples in order to explore the communication of HIV-positive status in this health context. However, the researcher was only able to interview one sero-discordant couple in which the man was HIV-negative and the woman was HIV-positive, and the issues they raised seemed similar to those discussed by the HIV-positive informants.

The researcher also sampled workers from the collaborating agencies who were willing to talk about their experiences of working with members of the theoretical population. The aim of including the service providers was to explore their perspectives on the needs of service-users.

2.4.4 Study location

The study was based in London, because of its relatively high proportion of immigrant Black African residents (Forde & Cook, 2013) and people living with diagnosed HIV (Forde & Cook, 2013; HPA, 2009, 2010, 2012b). London also has a well-established network of community-based organizations offering HIV-related services which provided suitable recruitment opportunities and access to participants with diverse socioeconomic backgrounds and experiences of living with HIV. Research undertaken in this location provides evidence about the perspectives of those who have available to them the most fully developed configuration of services in the UK.

The organizations targeted were those with HIV-related services accessed by Black Africans and who were willing to facilitate access to study participants. Ten of the 14 organisations contacted initially agreed to facilitate participant access, but only five eventually did so. Hence, it must be acknowledged that the settings through which individuals were recruited were themselves self-selected, introducing a potential but unknown source of bias into the study. Although the initial intention was to recruit participants from both the NHS and community organizations, efforts to gain access to the NHS services in London were unsuccessful. Recruitment

through the NHS could have broadened the social composition of the sample by potentially accessing individuals who were ordinarily reserved about their HIV status. The researcher tried using snowballing to diversify recruitment avenues, but this approach yielded only individuals who belonged to different HIV support groups. The findings may have been biased towards HIV-positive individuals who were relatively open about their condition. However, as the findings chapters will show, most (14/18) HIV-positive research participants adopted some degree of concealment, despite of being members of HIV support groups.

2.4.5 Participant access and recruitment

This subsection discusses how the researcher accessed and recruited the three categories of participants described above: KCPs; their wives or partners; and workers from the community organisations. Potential respondents were offered reimbursement of expenses plus £20 in compensation for their time.

2.4.5.1 Recruitment of the KCPs (N=11)

The researcher sent study fliers (Appendix 1) and the KCP information sheet (Appendix 3) to his contacts at the five organizations, who sent them to all their service-users with East-African (Kenya, Uganda, Somalia, Sudan, Rwanda, Burundi and Tanzania) backgrounds. In addition, the contact people in two of the organizations posted the study fliers on their notice boards and took some to their HIV-support group sessions.

KCPs who were interested in possible participation got in touch with the researcher who fully discussed the study and what would be expected of them, as explained more fully below in relation to ethical considerations. It was difficult to determine the proportion of those who responded to or declined the invitation to consider taking part in the study because the researcher had no idea how many service-users accessed the relevant community organizations, and how many actually received the information sheet. The sample was therefore made of individuals who were

doubly self-selected, because they had chosen to join an HIV support group and had then opted to take part in the study. In addition to the 11 KCPs recruited, two potential respondents dropped out of the study, one because of a change of mind and one because he travelled to Africa at the time when the fieldwork was being undertaken. The researcher had intended to recruit part of the sample through the NHS but failed to do so due to the access challenges described above. All these factors narrowed down the social composition of those interviewed, rendering the sample less representative of the population explored. Sampling limitations will be reviewed in more detail in the discussion chapter.

2.4.5.2 Recruitment of wives and partners (partners) (N=6)

After their interview, KCPs were asked if they were willing for their partner to participate in the research, and, if so, asked to take an information pack to them. Seven of the 11 KCPs agreed to do so, and four of these partners were eventually interviewed after the researcher had discussed the study with them. Two additional HIV-positive women were recruited directly, when the researcher was seeking sero-discordant couples, as part of theoretical sampling as discussed above. One of the two women was in sero-concordant relationship and the other one, described above, was in a sero-discordant relationship and her partner was interviewed as well. Perhaps unsurprisingly, the four participants who had transitioned into HIV awareness activists were more likely to involve their partners in the study than those who selectively concealed their status. Two of them facilitated access to their partners; one was willing to involve his partner but she was away in Africa; and the fourth was willing and tried to involve the partner in the study but she declined.

2.4.5.3 Recruitment of workers from collaborating agencies (N=5)

To recruit workers, the researcher contacted the relevant managers in the 14 organizations initially identified, to request permission to contact those of their staff members who were directly involved in services targeted at the study population.

Once the researcher received consent and suggested names from the managers, he directly called the relevant individuals to invite them to consider taking part, after discussing the study details. In some cases, the researcher knew which individuals to approach because he had previously worked with them on other projects. However, it was considered that this familiarity did not jeopardise the quality of the data because the individuals were previous project partners, not acquaintances. The researcher followed the same procedure for the information sessions and to seek informed consent, both for the interviews and potential follow-up phone call, as described above.

A total of eight individuals initially agreed to take part in the study. However, two could not honour interview appointments, citing work-related pressure. A third individual rescinded their agreement to participate in the study, citing personal issues. Three men and two women were recruited and interviewed as service providers. One of the five service providers interviewed was white British and the other four were Black Africans, originally from Eastern or Southern Africa. Four of the five organisations from which the service providers were recruited also facilitated the recruitment of the KCPs.

2.4.6 Ethical issues

The study received ethical approval from the Human and Health Sciences' School Research Ethics Panel (SREP), at the University of Huddersfield (Appendix 20). As described above, the study did not include recruitment from the NHS because the researcher could not gain access to NHS services. Furthermore, the study did not involve any clinical records of the participants or the NHS staff. All contact with the employees of the NHS was only in their capacity as workers or volunteers in the voluntary agencies. This decision was endorsed by the University of Huddersfield Ethics Committee, who granted the study the ethical approval. The following paragraphs further discuss specific ethical considerations and how they were addressed in the study.

2.4.6.1 Informed consent

The researcher provided prospective participants with information sheets which were followed up with meetings or telephone conversations in which the researcher discussed the study details and what participation would mean. He explained that the study was for academic purposes, and that, although it could directly or indirectly lead to changes in policy and practice, it would not benefit them directly. The researcher made it clear to potential respondents that taking part in the study was voluntary, that they were free to withdraw at any time without having to give any explanation, and that they could opt to have existing data erased.

However, it was difficult to assess the levels of understanding gained from the information sessions. The researcher sometimes had to repeat the information, and sometimes used a second language (Kiswahili), whenever appropriate, to ensure that the participants concerned had developed an adequate understanding of what their involvement in the research would entail. During these discussions, the researcher also informed the prospective participants about any potential dangers involved in taking part in the study, such as recall of their emotional past. The researcher informed each participant, apart from the workers from the service provider agencies, that a trained counsellor would be freely available should they require emotional support as a result of discussing potentially distressing issues.

Some of those approached were reluctant to sign the consent form (Appendix 6) even though they were willing to take part in the research because they were uncertain about who else would have access to the forms. To resolve this potential impasse, the researcher reverted to reading out the informed consent statement to the participants and audio-recording their assent, with their consent.

2.4.6.2 Anonymity and confidentiality

Interview audio-recordings and transcripts were transferred into password-protected electronic files in a computerized system which was only accessible to the

researcher. All printed materials, such as verbatim transcripts, were securely locked away and destroyed as soon as they became redundant.

The researcher kept confidential, between himself and the participants, any information which could reveal their identity. For instance, he ensured anonymity by detaching the names of people, places, organizations and any other potential identifiers from the data, using pseudonyms to identify individuals. He ensured as far as possible that individuals could not be identified indirectly from the content of the interview extracts subsequently used in any written work. Where a KCP and their partner were interviewed separately, the researcher assured each respondent that whatever information they shared with the researcher would not be disclosed to anybody else in a form which would allow individuals to be identified, including their partner. The cases of two couples who chose to be interviewed conjointly are discussed below in relation to interview privacy.

The researcher will publish the findings of the study as truthfully as possible, with due consideration of the potential impact on the participants, the community and the profession. In reporting the findings, he will take care to avoid reinforcing prejudice about a stigmatized group of people (Anderson, 2008; Elford et al., 2008).

The researcher gave the participants an opportunity to validate the findings through member checks, as discussed above. However, the researcher informed the participants that this thesis and any other reports resulting from the study might not fully represent their views because they would reflect his interpretations of their perspectives (Rossman & Rallis, 1998).

2.4.6.3 Ensuring interview privacy

To ensure privacy, interviews with HIV-positive respondents were, wherever possible, conducted at neutral premises away from the participants' homes. Interviews at home could, for example, lead to unintended disclosure of sensitive information, should other family members overhear what was said. However, the researcher did end up conducting six out of the 18 interviews at participants' homes. Three couples wished to be interviewed jointly at their home for various reasons,

although one of these couples eventually agreed to be interviewed separately, but again in their own home. The third couple and one other male participant did not want to travel to any venue away from their homes for the interviews but were happy to be interviewed at their homes. Eleven other interviews took place in private meeting rooms on the premises of the collaborating community organizations. Participants in joint interviews were advised to share only what they were happy to reveal, and to keep confidential whatever was discussed during the interviews.

2.4.6.4 Risk assessment and minimization

Before going into the participants' homes, the researcher contacted a third party and indicated the anticipated interview duration. At the end of the interview, the researcher again called the third party to inform them of the interview's completion. The researcher also conducted a generalized interview venue assessment to check for any causes for concern, such as broken furniture or threats to privacy. All the at-home interviews were devoid of incidents.

During the interviews, the researcher remained sensitive to personal issues and was alert at all times for cues of distress from the participants. Throughout the study, he maintained an awareness that it explored sexual health issues which, to some participants, were embarrassing to talk about, and could lead to the recall of traumatic circumstances. Three participants broke down in tears during the interviews. This prompted the researcher to pause the sessions to allow them time to regain their composure. He checked with them that they were able to continue with the interview, and all three chose to do so. Some of the participants expressed a sense of guilt and shame for having HIV. The researcher assured such participants that the study's aim was not to judge them, but rather to explore their perspectives on the realities of living with diagnosed HIV in the family and their support needs.

The researcher provided participants with contact details for counselling services and a direct helpline where they could get support after the interview. None of the participants' indicated that they needed the support immediately after the interviews, including those who cried during the process. However, the researcher advised all

the participants that they could access these services directly at any time, with or without informing the researcher. There were no cases in which participants provided information that warranted action to safeguard vulnerable individuals.

2.4.7 Data collection procedures

As discussed above, in-depth interviewing enabled the researcher to explore the participants' experiences and understandings of living with diagnosed HIV in the family; and to learn about the perspectives of the support workers on how HIV affected their service-users and how services could better respond to their needs.

At the beginning of each interview, the researcher ensured informed consent by reading out the consent form, as described above. The researcher began the interview sessions by asking the participants for background details, which required short factual responses, using a demographic questionnaire (Appendices 7 and 9). The researcher used interview topic guides (Appendices 8, 10 and 11) to steer the initial interview discussions. A loosely-structured topic guide, rather than a highly-structured schedule was used, in order to keep the interviews conversational and allow the participants to freely provide detailed accounts of their own experiences, in adherence to grounded theory design. During the course of the interviews, questions were progressively modified to clarify earlier responses and develop any promising lines of enquiry. In the interviews, the researcher developed follow-on questions as appropriate, in order to reflexively explore issues raised by the respondents, and to explore issues which he had not anticipated.

The interviews were audio-recorded with the respondents' consent. However, one participant declined to be audio-recorded, prompting note-taking during the interview. In two cases, the participants used Swahili, a common East-African language, to express their views more fully. One participant used Luo and another Luganda, both native dialects in East Africa, to express meanings they felt could only be best conveyed in their own dialects. The researcher, who was familiar with these languages, translated such expressions into English during transcription. The one-to-one interviews lasted about an hour, whereas the joint interviews with

couples lasted for approximately two hours. The participants responded differently to face-to-face interviews. For instance, the first three KCPs and the partner to KCP2 were very confident in discussing their circumstances. They were individuals involved in frontline HIV awareness and prevention activism. The fourth KCP was less outspoken and was the person who had declined to be audio-recorded because he did not entirely trust the promise of confidentiality.

After every interview, the researcher sought the participants' permission to ring them back at a later date in case he needed clarification or additional information during data analyses. All the participants consented to the request for follow-up telephone contact. The researcher used the follow-up telephone calls to collect additional data. At the end of the data analyses, the researcher also used member checks for further data collection and verification of the findings, as outlined above. The researcher offered prospective participants £20 in compensation for their time.

2.4.8 Data analysis

The previous subsection discussed the use of in-depth interviews to collect the data that informed the present study. This subsection focuses on data analysis using Strauss and Corbin's (1990) cyclic three-step analysis guidelines. The aim of data analysis was to develop better understanding about how members of the theoretical population managed living in families in which the man was HIV-positive. The researcher strove to keep in the foreground participants' concerns, and to minimize the researcher effect, as discussed under reflexivity and relationality. As outlined below, analysis eventually focused on the issue of communicating HIV-positive status.

Data analysis began with open coding, the inductive identification of codes, short descriptor statements used to group data items (Wuest, 2012) in terms of their overall meaning (Sbaraini et al., 2011) in a process herein called coding. During the coding process, more than one code could be assigned to identified units of meaning, as discussed below. The researcher used constant comparison and questioning techniques to make theoretical comparisons (Cranelly, 2009), as

described above. Once the codes and concepts, the conceptual labels assigned to discrete instances of the subject under investigation (Strauss & Corbin, 1990), emerged from the analysis, they were compared and contrasted to check their relevance to the developing theory. Ultimately, codes were grouped into abstract categories that highlighted the realm of the study, albeit descriptively. The researcher also referred to the literature to check for similarities and differences between the literature and the emerging theory. For example, the researcher briefly reviewed literature on multiple illnesses as an emerging category, to compare the kinds of illnesses reported in the literature with those reported by the present participants, such as diabetes, sexual dysfunction and liver and kidney problems. In cases where the findings were unclear or the researcher could not fully understand the participant's views, follow-up phone calls were made to solicit clarification. For example, when housing emerged as a relevant category, the researcher phoned back several participants to find out about any issues associated with their tenancy arrangements. In the subsection that follows, the researcher describes the process of open coding as the first stage of the cyclical three-stage data analysis approach used in the present study.

2.4.8.1 Open coding

Open coding refers to the “process of breaking down, examining, comparing, conceptualizing and categorizing data” (Strauss & Corbin, 1990, p. 61). The aim of using open coding here was to break up the data into small analytical chunks which could then be grouped, compared and contrasted.

The researcher began the process of open coding by listening to the audio files from the interviews repeatedly, to develop a mental map of the data. After each transcription, he read through the transcripts several times in order to develop a broader picture of the interview, identify key issues (Wuest, 2012) and enhance theoretical sensitivity (Strauss & Corbin, 1990, 1998). The researcher broke the data into small chunks containing a unit of meaning and attached a brief description to each, summarizing what was being said. Related items were grouped together in open-coding categories. Appendix 13 provides an example of the open coding

process carried out in the present study. Through constant questioning and constant comparison, the researcher acknowledged and strove to minimize the researcher effect on the data. As Strauss and Corbin noted, “fracturing data forces preconceived notions and ideas to be examined against the data themselves. A researcher may inadvertently place data in a category where they do not analytically belong, but by means of systematic comparison, the errors will eventually be located and the data and concepts arranged in appropriate classifications” (Strauss & Corbin, 1990, p. 13). Open coding gradually developed into axial and then selective coding, although these analytical processes overlapped. Details on how the researcher carried out axial coding are discussed next.

2.4.8.2 Axial coding

According to Strauss and Corbin (1990), axial coding refers to procedures through which data broken down during open coding are reconstituted in new ways by making connections between and within categories and exploring their dimensional ranges. This form of coding is called ‘axial’ because coding takes place around the ‘axis’ of a category (Strauss & Corbin, 1998). In the present study, the researcher developed many categories, for example alcohol use, medication issues, culture, communication with children, HIV-positive status disclosure and gender relations. The researcher began to link categories and to notice variations within categories, for instance between public and selective disclosure. In adherence to Strauss and Corbin’s (1990, p. 99) model on axial coding, the researcher asked of the data questions such as why, how or what were the outcomes of the action or interaction involved and in what context did the happening occur? He drew upon his previous experience and knowledge of HIV and its impact on the family in developing the categories further. The identified relationships between categories and their dimensional ranges were noted in memos.

During axial coding, the researcher moved back and forth between inductive and deductive interpretations. For example, the researcher noted from the data that most of the participants had not disclosed their HIV status to their children. The hypothesis on concealment from children was then deductively verified by the

literature. Appendix 14 illustrates how the process of axial coding was applied in the present study.

2.4.8.3 Selective coding

This was the most abstract stage of coding. Strauss and Corbin (1990, p. 116) defined selective coding as “the process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that needed further refinement and development”. The core category relates to a storyline concerning the central issue around which other identified categories are integrated (Walker & Myrick, 2006). As Strauss and Corbin (1990) argued, making a commitment to a storyline is particularly difficult because the researcher becomes so immersed in the data that everything begins to appear important. Data analyses identified communication about HIV status as the core category around which three important subcategories – HIV status disclosure, exposure and concealment - were organized as shown in Figure 0.1 presented in the Introduction to the thesis. These subcategories were related to other emergent categories, such as the social contexts of disclosure, concealment and exposure, and multiple stigmatization.

The issue of communication about HIV-positive status could be identified throughout the data. Participants’ narratives contained many references to whom they told and did not tell and who might or might not have found out about their condition; about their reasons for deciding whom they should tell; and about the consequences, as they saw them, of disclosure, concealment and exposure of their HIV-positive status. Communication regarding HIV status also influenced participant’s access to and use of HIV-related services, as will be discussed in the findings chapters.

2.4.9 Assessing rigour

The aim of this section is to discuss how the researcher did his best to ensure that the study methodology generated ‘good research’. Denscombe (2007) argued that any researcher must demonstrate the trustworthiness of their research as part of

the research process, because a researcher should never assume that readers would be sufficiently naive to embrace the research findings at face value, nor trust the researcher's word on quality as an act of faith. Lincoln and Guba (1985) maintained that the researcher as well as the research audience should be convinced the findings are worth paying attention to. Strauss and Corbin (1990) stated that a good qualitative study should explicitly detail its procedures in order to enable the readers to accurately assess the appropriateness of the resultant report. They identified three main ways of judging the rigour of a grounded theory study. Firstly, judgements should be made about the validity, reliability and credibility of the data. Secondly, the adequacy of the research process that generated the emergent theory should be reviewed. Thirdly, the strength of the empirical grounding for such a theory should be assessed. The rigour of the study is reviewed below in relation to the issues of credibility, transferability, dependability and confirmability.

2.4.9.1 Credibility

Denscombe (2010) argued that credibility is concerned with whether the data collected are the right kind for answering the research question. Credibility also refers to the extent to which the research findings reflect the research participants' views as accurately as possible. Lincoln and Guba (1985) noted that a qualitative researcher cannot prove in absolute terms that they 'got it right', but can only show how they strove to make their theory as accurate as possible. The following paragraphs therefore discuss the researcher's efforts to do just this.

First of all, the data was grounded in the participants' own perspectives. Theoretical sampling ensured that data sources were relevant to the emerging theory and that the ensuing data interpretations remained grounded in the participants' perspectives and relevant to the research question. After conducting an iterative process of data collection and analyses, the researcher became entirely immersed in the data, and was able to develop a detailed scrutiny of the transcribed interviews and the contextual data gathered through observations during fieldwork (Appendix 16). The field notes, together with memos and transcripts, were used to develop concepts and categories through constant comparative analysis, as discussed above. By

these means, the researcher was able to develop a deeper understanding of the different meanings the participants attached to their diverse circumstances involving life with diagnosed HIV in the family.

As discussed, the researcher also used member checking to enhance the credibility of the data. He summarized the key findings in a simplified accessible English language (see Appendices 24 and 25), and sent them to those participants he was able to contact in order to obtain their feedback on the findings. Overall, 11 participants of the original sample provided feedback on the findings; four of them through emails and the rest through telephone/Skype interviews. The 11 participants included four services providers, five KCPs and two partners to the KCPs. As Denscombe (2010) suggested, member checking gave respondents the opportunity to comment on the validity of the research conclusions about communication of HIV-positive status. The participants who responded to member checks corroborated the findings. Although less than half of the original sample, their views were important in the development of the emergent theory on communication about HIV status because the study was not aimed at gaining a representative view of the study population; but rather exploring what it meant for the affected families to live with the diagnosed HIV. Whilst obtaining this feedback, the researcher took the opportunity to ask respondents about any changes in their circumstances or perspectives which might have occurred since they were interviewed. None of the participants reported any changes in their responses to communication about their HIV status. However, two KCPs said they were happy because they had since been granted indefinite leave to remain in the UK and were looking for jobs. The researcher also used peer reviewing (E. Thomas & Magilvy, 2011) to ensure credibility by seeking feedback from a very experienced supervisory team on the data analysis procedures and detailed interpretation of the interview transcripts.

During the interviews, the researcher allowed the participants to express their views fully without adhering to specific interview structure, using a loosely-structured interview guide. Although probing can interrupt participants' flow of ideas, it was used to gather more details on the participants' narratives that needed clarification during the interviews. The researcher also used follow-up telephone interviews to gain further insight into the participants' views on issues that were found to be

incomplete during the data analyses, as illustrated below with an example in which a participant spoke of 'difficulty' without being explicit.

Robin: *“And then when again you go down to, to to be away from her, life becomes so difficult you get depressed.”*

It is difficult living alone. You don't get wife support like cooking. You end up in poor health. No one to motivate you to eat well, avoid alcohol. Things like that.

(Robin; 45 years old, HIV-positive for 13 years, lives with wife Harmony; 48 years old, HIV-positive for 14 years, and their 3 children. Have 6 children in total, 4 of whom are Harmony's late sister's children)

A follow-up phone call elicited the response shown in bold, which provided clarification about what a 'difficult life' meant to this respondent.

2.4.9.2 Transferability

Whereas quantitative methods rely on the generalizability of the findings from representative samples, qualitative research uses an alternative which Lincoln and Guba (1985) called transferability. Transferability is an imaginative process in which the research audience use the information given about the study context to judge how far the findings should be transferred to similar instances. In this case, it refers to the prospect of applying the present findings to other related contexts. Thomas and Magilvy (2011) argued that, like hedgehogs, qualitative researchers focus their attention on depth by identifying one phenomenon and focusing deep. However, Denscombe (2010) observed that the narrow focus casts doubt on the sample representativeness and how the findings from just a few cases could be replicated in another setting with similar cases. The reader of this thesis should be able to evaluate the detailed account of the problem area, research questions, study design, participants' characteristics, and the study site provided above; and so to judge the transferability of the findings to other settings with similar theoretical populations. As noted in the Discussion, the findings may be widely relevant to communication about the presence of other stigmatized but concealable attributes.

2.4.9.3 Dependability

Dependability refers to the extent to which the research methodology would produce similar conclusions about the same phenomenon on different occasions. Denscombe (2007; 2010) noted that a qualitative researcher's 'self' tends to become almost an integral part of the data collection technique, which raises the question of whether the same results would be arrived at if someone else did the same research. Denscombe (2010) argued that to achieve dependability, the research process should be made auditable. The researcher should therefore explicitly outline their methodology, articulating the lines of enquiry that led to the research conclusions, and should offer a reflexive account of their own role in the production of research data.

The methodology of the present study has been carefully articulated. The researcher has provided a reflexive account which allows readers to consider the possible impact of researcher-participant interactions on the study findings. Additionally, field notes were used to capture important issues that were not necessarily audio-recorded, such as the general appearance of the participant's home.

2.4.9.4 Confirmability

According to Thomas and Magilvy (2011), confirmability is attained once credibility, transferability and dependability are established. Confirmability is concerned with objectivity, the extent to which qualitative research findings are free from the influence of the researcher. However, as Charmaz (2006) noted, the researcher's values, identity and beliefs are inevitably part of the research process. The researcher endeavoured to conduct the data analyses with an open mind. He actively pursued data that did not seem to fit into the emerging storyline. For example, women were generally more likely to disclose their HIV status to at least one family member. However, two female participants were adamant they would

never disclose their status to their immediate family, a position found more commonly among the men. On further probing, the researcher realised that this reticence arose from particular family circumstances. One of the women believed that her family's religious background perceived HIV-positive individuals such as herself as immoral. Thus she didn't want to taint her family's image in the eyes of the community. The second woman concealed her condition from her family members because they depended on her for financial support and would be distraught, since HIV was still a death sentence in her village, while she was in fact benefitting from effective treatment in the UK. Incorporating this 'anomaly' into the overall storyline about gender differences in communication enriched the overall analysis by documenting its sensitivity to contextual factors.

2.5 Summary

This chapter has explicated how the present study was carried out and justified the adoption of the chosen methodology. It has explained why symbolic interactionism was chosen as a suitable framework for understanding what it means for the immigrant Black East-African men and their families in the UK to live with diagnosed HIV. The chapter has also discussed the generation of substantive and formal theories which are rooted in the participants' own experienced worlds through the application of modified grounded theory. The chapter has justified the choice, and discussed the use of, loosely-structured in-depth interviews as an appropriate research method for enabling research participants to fully discuss their perspectives. The need to incorporate reflexivity and relationality in a modified grounded theory study, so as to reflect the participant-researcher interactions and relationships in data constructions, was also discussed. Additionally, the challenges faced in applying relationality and reflexivity in the present study, particularly the risk of respondents and the researcher making general assumptions about their common knowledge, were outlined. Finally research rigour has been considered in relation to providing an audit trail for the credibility, transferability, dependability and confirmability of the present findings.

The next part of the thesis will discuss the study findings. After a short preface, three chapters will consider in turn each of the three thematic categories of disclosure, concealment and exposure, around which the substantive theory underpinning this thesis was formulated.

PART TWO

FINDINGS AND **DISCUSSION**

FINDINGS

Overview of the three findings chapters

This part of the thesis presents the research findings. This study aimed to explore what it means for London based immigrant Black East-African men and their families to live with diagnosed HIV; and to develop proposals about how services might better respond to the needs of such populations. Through theoretical sampling, communication of HIV-positive status was identified as the focus for analysis. This introduction provides an overview of the main findings. The following three chapters each address different but inter-related facets of the difficulties faced by some of the participants around communicating their HIV-positive status to others: disclosure, concealment and exposure.

Chapter 3 will be concerned with disclosure, illustrating that some of the participants faced an ongoing dilemma in deciding whom to reveal their HIV-positive status to, and if they did decide to do so, when, how and why to share the information. In revealing their illness, they risked rejection and stigmatization; whereas concealment created the risk of exposure of their HIV status to unwanted recipients. Furthermore, concealment of HIV status could exclude potential sources of support. A key concern was that by disclosing to particular others who themselves might not keep the information confidential, they risked losing control over who else might know. Disclosure to health and social care professionals carried a degree of guaranteed confidentiality but disclosure with no guarantee of confidentiality was necessary for accessing other support which was forfeited by those who concealed their status. Whether they disclosed or concealed their HIV status, the concerned participants faced a constant risk of exposure to unintended recipients. Although the dilemma of HIV status disclosure is universal, it was a heightened concern for the present study population, many of whom were socially stigmatized in other ways. Living in British society with marginal immigrant status and associated challenges, such as racism and lower socioeconomic standing, often led to negative public and self-perceptions, as discussed in the section on stigmatization in Chapter 1. To

manage their disclosure dilemma as best they could, many of the research participants carefully assessed the trustworthiness and supportiveness of potential confidantes before revealing their condition. But, as will be seen, they could only test their assessments by communicating that information irreversibly.

Chapter 4 will discuss concealment of HIV status and will show that some of the participants obscured their illness from, among others members of the general public, parents, sexual partners, siblings, their own children, neighbours, housemates, workmates and friends. The affected participants used various tactics to conceal their condition, including the safe storage of all HIV-related materials and the avoidance of social contacts. Most of the participants did not have any discernible signs of HIV due to accessible and effective treatment, and so were able to conceal their status from specific individuals if they chose to do so. For some, the distance between the UK and their native countries aided their efforts to conceal their infection from friends and family members in their countries of origin. Some participants revealed their diagnosis to particular others when they feared that it was about to be exposed anyway. Others chose the services they accessed carefully in relation to the risk of exposure, for example avoiding settings in which people from their country of origin were likely to be present. Four research participants had transitioned from selective disclosure to becoming HIV awareness activists who had 'come out' publicly and sought to confront HIV stigmatization.

Chapter 5, the third and final findings chapter, will focus on exposure. This chapter will illustrate that, apart from the four men who had opted to reveal their HIV-positive status, the research participants were constantly attempting to manage the risk of unwanted onward exposure, both by those to whom they had previously revealed their condition, and through giving off cues such as the presence of medicines. The perceived potential onward exposers were mainly those close to the infected individual, such as family members, friends or workmates in a position to detect clues to the illness. Unlike disclosure or concealment which involved intentional decisions by the relevant participants, exposure was beyond the control of the individual. This chapter will also show that affected participants assessed the risk of exposure, based on their interpretation of the motives of potential exposers.

Furthermore, when it did occur, they differentiated between malevolent and benevolent exposure.

These three categories are key to understanding how these participants managed information about their condition, and we begin in Chapter 3 by discussing HIV-positive status disclosure.

CHAPTER THREE

DISCLOSURE

CHAPTER THREE.

DISCLOSURE OF HIV STATUS

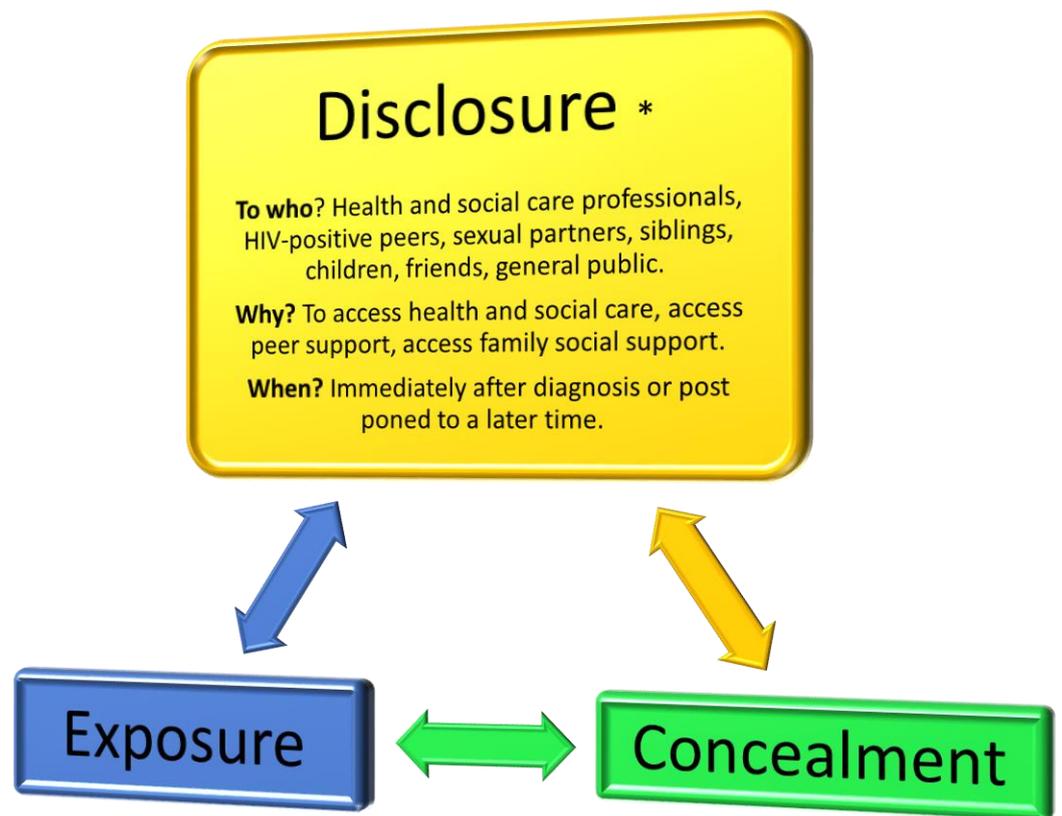
3.1 Introduction

This chapter presents an analysis of the findings concerning HIV-positive status disclosure. It consists of two main sections, the first of which considers the social contexts of disclosure, and is divided into subsections addressing four categories of people to whom the participants disclosed their diagnoses, namely health or social care professionals, HIV-positive peers, family members and members of the general public. The second section discusses the timing of disclosure, that is, when the participants chose to disclose their HIV status to these people.

From their own accounts, positive sero-status disclosure was a major issue that influenced the participants' lives in multiple ways, including the kind of relationships they maintained with the recipients of the disclosure, and the services they subsequently accessed. Although disclosure was sometimes necessary for survival with HIV, it could also lead to harmful consequences, such as rejection and stigmatization by the people in whom they had confided. Consequently, apart from four people who declared that they were comfortable disclosing their condition to anyone, life with HIV for the rest of the participants involved constant reflection on whom to disclose their condition to. This decision was based on their perceptions of the attitudes of the potential recipient of disclosure and their prospective reactions. For most participants, life with HIV meant an ongoing dilemma of risking rejection and stigmatization by making their status known in order to gain access to various services; or avoiding those risks by keeping their diagnosis secret and forgoing the support they need to live with HIV. Either way, the relevant respondents faced a risk of exposure irrespective of their decisions to reveal or conceal their HIV-positive status. As outlined above, the decision to disclose HIV-positive status entailed risk because disclosure is irreversible - once the information has been shared, it can never be withdrawn. The individual revealing their diagnosis can only wait to deal

with the consequences, however good or bad. Further, disclosure of HIV-positive status did not guarantee that an individual would get the support they needed. For instance, one male and one female participant had received negative reactions from a brother and a friend respectively, and lamented the fact that it was too late to change their minds about disclosing to them. The above discussions highlight a complex interconnection between disclosure, concealment and exposure, as illustrated in Figure 3.1 below.

Figure 3.1: Multiple relationships between disclosure, concealment and exposure



*The disclosure box is expanded to reflect issues relevant to the present chapter. The same issues are explored in different contexts in Chapters 4 and 5.

This chapter discusses how participants were more likely to confide in those whom they believed would be supportive. Table 3.1 below uses tabulated quantitative data to illustrate that such individuals included carefully selected family members and friends; their peers at HIV support groups; and health or social care professionals, by virtue of their role in HIV treatment and care. Sixteen of the 17 HIV-positive participants, 94%, had revealed their condition as a prerequisite for joining HIV support groups. The participants also reported high rates of disclosure to sexual partners, with 82% (14 of the 17 HIV-positive participants) having disclosed their condition to their sexual partners. Very few of the participants had disclosed their HIV status to parents, children, friends and other family members, as will be discussed further below.

Table 3.1. Reported disclosure and the disclosure recipients (N=18, 1 participant HIV-negative)

Participant's details			Disclosure recipients												
Participant	Gender	Age	Disclosure	Support groups	Partner	Parents	Brother	Sister	Children	Other family members	Friends	GP	Social carers	Dentist	Public audience
Paul	Male	51	Yes	1	1	1	1	0	0	0	0	1	0	0	1
Robin	Male	45	Yes	1	0	0	0	0	0	0	0	1	0	0	1
Troy	Male	57	Yes	1	0	0	0	0	0	0	0	1	0	0	1
Luke	Male	41	Yes	1	1	0	0	0	0	0	1	1	0	0	0
Dan	Male	49	Yes	1	1	1	0	1	0	0	0	1	0	0	1
Damien	Male	52	Yes	1	0	0	1	1	0	0	0	1	0	0	0
Bill	Male	31	Yes	1	1	0	0	0	0	1	0	1	0	0	0
Trevor	Male	47	Yes	1	0	0	0	0	0	0	1	1	1	0	0
Biden	Male	43	Yes	1	1	0	0	0	0	0	0	1	0	0	0
Phill	Male	51	Yes	1	1	0	0	0	0	0	1	1	0	1	0
Tyron	Male	45	Yes	1	1	0	1	0	0	0	1	1	0	0	0
Robert	Male	40	No	0	0	0	0	0	0	0	0	0	0	0	0
Millie	Female	54	Yes	1	1	0	0	0	1	0	1	1	0	0	0
Lorna	Female	52	Yes	1	1	0	0	1	1	0	0	1	0	0	0
Rachel	Female	37	Yes	1	1	0	0	0	0	1	1	1	0	0	0
Harmony	Female	48	Yes	1	1	0	0	1	1	0	0	1	0	0	0
Melisa	Female	43	Yes	0	1	0	0	0	0	0	0	1	0	0	0
Lucy	Female	35	Yes	1	1	0	0	0	0	0	0	1	0	0	0
Total	-	-	-	16	12	2	3	4	3	2	5	17	1	1	4

Family members and friends are likely to provide emotional support or practical assistance, whereas peers are supportive through shared experiences of living with

HIV. Professionals, on the other hand, are supportive in their provision of services. The findings suggest that an HIV-positive individual constantly weighs the benefits against the risks of disclosure in order to decide which option promises better outcomes. The discussion below also illustrates gender variation in disclosure. Women were generally more likely than men to disclose their own or their family members' HIV infection, with some of the women providing a voice for the men who felt unable to reveal their own HIV status. Furthermore disclosure to children among the present participants was done entirely by women.

Caution must be exercised about interpreting quantitative data derived from qualitative research on non-representative samples. However, the one statistically significant relationship found between age or gender and disclosure/concealment/exposure fits with interview narratives. None of the 11 HIV-positive male informants reported disclosing their condition to children, whereas 3 of the 6 women did so ($P < .05$, Exact Test, two-sided). In contrast, although the relationship was not quite statistically significant, it is noticeable that all of the four research participants who had 'come out' publicly were men. This difference might be due to chance, or arise from the sampling process, since men were recruited directly, whilst 5 of the 6 women included in the study were approached through their partner. But the two findings in combination are suggestive of a traditional role difference which might well be found to a greater or lesser extent in other cultures between women who take primary responsibility for child-care and men who orient themselves more towards the extra-familial social world.

The following section discusses the social relationships within which some of the participants disclosed their diagnoses.

3.2 The social contexts of disclosure

By the time they took part in the study, apart from the four participants who were open about their HIV-positive status, the remaining 14 participants had all told a number of selectively chosen confidants about their or their partner's HIV-positive

status. As outlined above, the respondents faced an ongoing dilemma over whether or not to disclose their diagnosis to the people with whom they interacted. Overall, disclosure was aimed at carefully selected individuals, based on the participants' perceptions of their responses and anticipated levels of support. Apart from HIV clinicians, who knew of the diagnosis by virtue of their role in HIV care, all the participants had disclosed their HIV-positive status to selected health and social care providers such as GPs, social support workers, dentists and nurses. Sixteen of the 17 HIV-positive participants had also joined HIV support groups, thereby revealing their infection to peers and to the workers through attendance at such groups. The research participants had also, variously, disclosed their diagnosis to sexual partners, siblings, children and religious leaders. Three of the 12 HIV-positive men included in the study had also told friends living in England, and one man had told a friend in his country of origin. Disclosure was therefore an individualized, selective process that varied among the participants.

The disclosure recipients, the people to whom the participants had disclosed their HIV status, could be divided into two categories: those whom the participants knew to be HIV-positive; and those whose HIV status was unknown to the participants. The recipients in this first category had usually met through HIV support groups where both parties accessed psychosocial support. Those in the second category, whose HIV status the participants did not know, included health and social care professionals, family members and friends.

The participants' disclosure strategies depended both on whether they believed the person in whom they intended to confide would provide support, and whether or not they suspected that the disclosure recipient had HIV. The participants attempting to conceal their condition tended to assume that other HIV-positive individuals would be more supportive and were likely to reveal their status to such individuals. Some participants reported instances when they disclosed their status to an individual whose status they did not know, only to learn that the person was also living with HIV. The following analysis focuses on the various categories of disclosure recipients to whom the participants revealed their positive sero-status.

3.2.1 Disclosure to seek healthcare

Disclosure to health and social care professionals was a matter of necessity rather than choice, a means to accessing vital treatment and care. However, the following discussion will exclude HIV clinicians because they are more likely to be the initial providers of diagnosis information. Disclosure could be more problematic in relation to healthcare providers who were not HIV specialists, for example GPs, nurses, health advisers and dentists.

All the participants indicated that their GPs knew they had HIV, as illustrated below.

Interviewer: *Who knows that you have HIV?*

Luke: My GP... because my GP is aware of my HIV, I go there a lot when I am depressed. Sometimes you just feel you cannot go it alone. I mean living with HIV.

(Luke, 41 years old, HIV-positive for 11 years. Has separated from partner because of HIV, has no children)

Four of the 16 HIV-positive participants were originally diagnosed while still in their countries of origin in Africa, before they relocated to the UK, where they again tested positive for HIV. The remaining 12 were all first tested for HIV in the UK. All of the research participants had informed their GP about their HIV-positive status. Three stated that they had tested for HIV through GP referral, and subsequently revealed their positive diagnosis to their GP. The rest of the participants, those who had not been diagnosed through GP referral, informed their GPs about their condition. GPs provided an important care pathway for participants because, as well as prescribing ARVs and referring for periodic check-ups at HIV specialist clinics, they also dealt with many of the participants' other general health concerns. As illustrated by the above quotation from Luke, the GP was the first point of contact for common health concerns such as depression. Consequently, many participants believed that it was important for their GP to be aware of them being HIV-positive so that they could receive effective general healthcare. However, disclosure did not necessarily always result in suitable care by some GPs, as illustrated below.

Phil: *I am not getting on well with my GP. Because I am HIV-positive, whenever I go there, like I have headache, ... whatever I complain to her, she is always telling me, 'That's your HIV. You do not know you are HIV-positive. So, let me give you some painkillers. I have nothing to do for you. Why don't you go and see your consultant.'* [Sarcastically mimics the GP].

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of origin from previous marriage. None of the children are known to be HIV-positive)

The above extract suggests that HIV care differed between professionals, as did the expectations of those seeking care. Phil disclosed his status to his GP in order to facilitate better care, but instead he experienced what he believed to be stigmatization. He was worried that any future health concerns would be dismissed by the GP as related to his HIV-positive condition. This example highlights the risk of potential stigmatization which could lead to future concealment of HIV status, poor health outcomes and a lack of access to healthcare by the concerned participant.

In spite of such risks, participants such as Phil revealed their illness to their GP and other healthcare professionals in order to access services, resulting sometimes in access to the necessary care, and sometimes in perceived rejection and stigmatization, as illustrated below.

Troy: *I mentioned to the nurse that ... I am HIV-positive and I need some medication. Is it possible to see a doctor, do you have HIV consultant whom I can talk to about my medication? Within that time, I was even moved to isolation room. From that time, the services totally deteriorated, almost not there. Out of nowhere, I was even, about 9 o'clock at night, they discharged me.* [Participant's experience at a major hospital in England in 2009]

(Troy, 57 years old, HIV-positive for 12 years, has 5 adult children, 2 living with their mother in England, 3 living in different countries in Africa. Separated from partner because of HIV. None of the children is known to be HIV-positive)

Apart from being HIV-positive, Troy also suffered from pancreatitis and diabetes. He said he was admitted to a major London hospital in 2009 because of a diabetes-related complication. However, because he was very poorly, he omitted to take his anti-HIV medications with him when he was taken into hospital. When he regained

consciousness, he disclosed to a nurse caring for him that he was HIV-positive and asked for her help in getting the correct medication. Troy believed the treatment he received thereafter was discriminatory and stigmatizing. This account was similar to Phil's about his GP, illustrated in the previous extract. In Troy's view, disclosure did not grant him the services he needed. Furthermore, he believed that the level of care that he had been receiving in relation to his primary reason for hospitalization was reduced after the disclosure.

Most participants said they had been referred to health advisors for further support soon after diagnosis by an HIV specialist. HIV health advisors in London work closely with specialist clinics to provide emotional and practical support to newly diagnosed individuals. Participants disclosed their HIV status in order to access such support, as illustrated below.

Damien: He sent me to a health advisor who told me I was not the only one with HIV. She said there are many people living with HIV, that there is medication, that people with HIV now live longer. People don't die anymore ... So the health advisor referred me to the support groups. She travelled with me to a certain organisation [participant keeping its identity confidential]. I met lots of people. Most of them were HIV-positive, they had families, and some had jobs.

(Damien, 54 years old, HIV-positive for 7 years, has 4 children in country of origin from previous marriage. Previous partner died of AIDS related illness in country of origin. Has partner, Lorna who lives independently from him in London, 52 years old, HIV-positive for 11 years, has 2 children. Lorna's 13 year old son who lives in London and Damien's 10 year old son who lives in country of origin are known to be HIV-positive)

Through disclosure to health advisors, Damien and others received assurance regarding their potential prognosis and gained access to support groups. None of the participants reported rejection or stigmatization by the HIV health advisors, a difference that could be explained in terms of the professional remit of the latter. Some respondents indicated that they had disclosed their HIV status to their dentists, against their wishes in some cases, as documented below.

Phil: Yea. It is like I went to register with a dentist. There is a form; they gave me a form to fill. There is where you get to and they ask you your status. I

did not fill that part. When I sent the form back, the nurse came back and said, 'You have to fill here. Why do you skip this one? We need to know your status before we register you' ... Otherwise, we are not going to register you.

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of origin from previous marriage. None of the children are known to be HIV-positive)

The above quote suggests that Phil unsuccessfully tried to avoid disclosure. He might have wanted to conceal his status but was pressurized by the nurse and obliged to give the information in order to access dental services. Phil said he had faced a similar dilemma before and was convinced he could not access dental services without sacrificing his confidentiality. Legally, it is not mandatory to disclose one's HIV status to a dentist in the UK. However, it is recommended that people living with HIV inform their dentist of their HIV status because of the potential risk of an adverse drug reaction, and to prevent any risk of onward transmission.

This subsection has illustrated that disclosure of HIV-positive status is an important gateway to healthcare services. However the discussion also highlights the risk of rejection and stigmatization which can result from disclosure even to health professionals. The next subsection analyses disclosure to other people living with HIV.

3.2.2 Disclosure to HIV-positive peers

Sixteen of the 18 study participants were members of various HIV support groups through which they were able to socialize with and get support from other HIV-positive individuals. Two participants had never joined an HIV support group. One of them was an HIV-negative man in a sero-discordant relationship, and therefore had no need to join an HIV support group. The second had confidentiality concerns regarding support groups within her locality, as further discussed below. The groups brought together HIV-positive peers who met regularly to share their experiences of dealing with the various everyday challenges of living with HIV, such as medication adherence and sexual relationships. Attending an HIV support group implied

disclosure of HIV-positive status by default, and more or less guaranteed that disclosure recipients would also have the condition or, if HIV-negative, be sympathetic to people who carried the infection. Being in London, with many well-resourced HIV support organizations, the participants had a choice of groups to join, giving them the opportunity to reveal their condition only at the services most relevant to their needs. But some of the participants remained wary of the perceived risk of exposure by virtue of membership of such groups and avoided certain services with which they associated a higher risk of exposure.

During the interviews, all of the participants were asked about who, as far as they were aware, knew they were living with HIV; and who had informed these individuals of their condition. The aim was to establish who, other than healthcare professionals, had been told by participants that they were living with HIV; and to determine any pattern regarding disclosure recipients. As already indicated, 16 HIV-positive participants, (11 men and 5 women) had disclosed their condition through association with support groups. The couple quoted below said they met at an HIV support group and subsequently married. They were interviewed together at home because concerns about confidentiality meant that they were not comfortable about being interviewed separately.

Interviewer: *And meeting there [at the support group] meant you knew your status and she knew your status or you discussed it again later?*

Bill: *Of course she told me.*

Rachel: *I think meeting there is a guarantee, at such a party. Yea.*

Bill: *It is a guarantee because most people who are meeting there, you have to be positive. Yea. So, that is how I met her.*

(Bill, 31 years old, HIV-positive for 7 years. Has partner, Rachel living with him in London, 37 years old, HIV-positive for 8 years. Bill an 18 months old son. The child is known to be HIV- negative)

Bill and Rachel said they met at a party organised by a London-based community organization for HIV-positive people. Although Rachel added that she later reiterated to Bill that she was HIV-infected, Bill noted that Rachel's status was obvious to him. Such 'automatic' disclosure through presence at an HIV support group is further illustrated below.

Interviewer: *And talking about status, how did you come to know that your current partner has HIV?*

Lorna: *My partner? My husband? ... My boyfriend?*

Interviewer: *Yes*

Lorna: *We met in the support group. HIV support group. I think everyone who is in support group has to be HIV.*

(Lorna, 52 years old, HIV-positive for 11 years. Has a partner, Damien who lives independently from her in London, 54 years old, HIV-positive for 7 years. Damien has 4 children from his previous marriage living in country of origin, previous partner died of AIDS related illness in country of origin. Damien's 10 year old son who lives in country of origin and Lorna's 13 years old son who lives in London are known to be HIV-positive)

The above extracts imply that disclosure by default was a key factor for participants in joining a support group, and that they valued being able to reveal their HIV-positive status in this way. Although some participants felt that support groups did not necessarily guarantee confidentiality, as will be illustrated below, the groups brought together peers more likely to respect one another's confidentiality, thereby minimizing the risk of unwanted exposure. Interviews with service providers emphasised that they strove to ensure that support groups adhered to high standards of confidentiality.

However, for some of the participants, the composition of some of the support groups was a barrier to accessing them. Melisa, one of the six female participants, had never joined a support group within her locality because she did not believe that her confidentiality would be guaranteed there. However, she did indicate willingness to join an HIV-support group away from her neighbourhood, such as West London. Although Melisa's approach exemplifies concealment, which will be discussed in depth in Chapter 4, her case is relevant to this subsection because it suggests that even those living with HIV might expose the status their HIV-positive peers.

Interviewer: *Do you attend any support groups?*

Melisa: *No ... because ... In East London I can't go there because East London people they are all from my country, so I can't go where my country mates are ... But if it on this side I can come this side [meaning West London] because I know nobody knows me this way ... So if I go and talk about my*

status they will talk all about it [in East London]. So everybody will be knowing it. Which I don't want.

(Melisa, 43 years old, HIV-positive for 13 years, has adult daughter. Separated from partner, Biden, 43 years old, HIV-positive for 11 years, has no child. Biden and Melisa still visit each other. Melisa's 13 year old son is known to have died of AIDS related illness in the UK)

As already illustrated, becoming a member of a support group entails HIV-positive status disclosure to other group members who might divulge this information to others, a risk which Melisa was not prepared to take. Her concern about disclosure at a support group leading to a risk of exposure was location-specific. She indicated that she was willing to join support groups in West London because she believed she would not be recognized by people in that area, hence raising fewer confidentiality concerns.

The next subsection discusses disclosure to family members.

3.2.3 Disclosure within the family

Some participants said they had disclosed their HIV status only to selected individuals within their families. It should be noted that members of the study population sometimes used the concept of family broadly, to include individuals who were not necessarily related to them in a way which would lead to them being categorized as family members in countries such as the UK. Culturally, some members of the present study population refer to individuals from their tribes or countries of origin as their family members. The following discussion is based on the participants' accounts of their relationships. Disclosure to family members differed depending on who in the 'family' the participants revealed their infection to and why they did so. All of the 16 HIV-positive participants had told at least one family member about their HIV status. In most cases, the family member most likely to be told was the sexual partner.

3.2.3.1 Disclosure to sexual partners

One reason which many of the participants gave for disclosing their HIV-positive diagnosis to sexual partners was to avoid partner infection or cross-infection. This concern was heightened by their knowledge that HIV transmission could become a criminal matter in the UK if one person infected another without having informed them that they were HIV-positive. However, disclosure to sexual partners prompted questions about infidelity and sexual history and sometimes led to relationship breakdown, as discussed below. Five of the 12 male participants had met their current sexual partners at the HIV support groups, and did not have to state their HIV-positive status, as discussed above. Finding sexual partners could be one of the benefits of joining a support group, although this issue is beyond the remit of the present research. However, some participants had had to personally disclose their infection news to their wives or partners.

Interviewer: *And how did you disclose to your partner?*

Dan: *Like I said I was so sick, and said I was going to test. And when I came back I said, like, I expected to be positive and I am positive. She somehow took it lightly but later on she also had attack of shingles and then she went for testing and she was found positive. So [pause] she started blaming me that maybe am the one who infected her.*

Interviewer: *As bluntly as that?*

Dan: *Yes ... I said I have been to Mildmay [hospital in country of origin]. They did this to me, I have been to this doctor, they said this. So it was like I was trying to tell her how things can improve. And then, soon, medication came out. 'These are the medications they have given me ... Now I am improving'.*

(Dan, 49 years old, HIV-positive for 12 years. Has 2 children in country of origin from previous marriage. Has partner, who lives with him in London, not interviewed. Dan has 3 children in London, one of them a step-daughter from the partner's previous marriage. Dan's 12 year old daughter in country of origin is known to be HIV-positive)

Dan's disclosure to his partner was in his country of origin where he first tested HIV-positive. As presented, his main concern had been her risk of being infected, which did ultimately transpire. He also wanted to reassure his partner about their health prospects. Explicit disclosure to the UK partner whom he had at the time of the study was unnecessary because, like many other participants, they met at an HIV support group.

Some of the men had to deal with the challenges of long-distance disclosure to a sexual partner living in their country of origin, as illustrated below. Such challenges include having to communicate such sensitive information via a long-distance phone call, having limited time to discuss implications or answer questions, and not being able to comfort or reassure one's partner. Phil, quoted below, had found this prospect so daunting that he had accepted the offer from his HIV counsellor to pass on the news that he was HIV-positive to his partner in country of origin.

Interviewer: *Apart from your friend ..., is there anybody else you told about the HIV?*

Phil: *My wife. It's only my wife*

Interviewer: *So how did you tell your wife back home?*

Phil: *Ah ... I talked to my counsellor that the situation where I am now, it's hard I have to tell my wife ... He said, "Oh its ok, I can tell her, I can talk to her, if you can't. For you it might be difficult to tell her" ... So one day he [the counsellor] told me just buy a calling card. We bought a calling card ... He [the counsellor] told her [Phil's wife] that, "Your husband [Phil] they took him to hospital, he was sick. So the doctors decided to do HIV test because they were giving him treatment and there was no change. So now the results came back and he is HIV-positive" ... The woman said "what? What?" [Laughs sarcastically] and started crying straight away. Saying, "Oh my God! Oh! So my husband went to London to die and I will never see him again!" ... Until he [the counsellor] told her "you don't have to cry. He is going to be all right. We have got medications here, will be all right you don't have to cry".*

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of origin from previous marriage. None of the children are known to be HIV-positive)

Phil did not feel able break the news to his partner about his disease and had relied on his HIV counsellor to do so. During the disclosure process, the extract suggests that the counsellor portrayed Phil as a victim of his circumstances. In using phrases such as 'he was taken', 'the doctors decided', and 'the results came back', the counsellor depicted Phil as a victim who had been struck down by a disease. Although Phil might have dreaded disclosing his own status, and further feared reprisal from possibly having infected his partner, the involvement of a third party possibly created a picture of a very ill and upset person who could not bring himself to discuss the disease.

This example also suggests differing assumptions about future prospects. Phil's partner immediately assumed that her husband was dying, and did not express concern about the risk that she might have been infected. During the interview, Phil noted that his partner had since tested for HIV and was negative. The preceding extract from the interview with Dan suggests that for those men living with their partners, at least there were indicators of the underlying illness, making the ultimate disclosure less of a shock for the recipient and possibly less daunting for the participant. However, in Phil's case such cues were not available. His partner might have assumed all was well with her husband in London until she received the phone call. This example also highlights the importance of psychosocial support services in the life of an HIV-positive individual. Without the support of the counsellor, Phil suggested, he might not have been able to tell his partner that he was HIV-positive, and she would not have known that she needed to be tested. This extract highlights common perceptions about what it means to be HIV-positive and the knowledge of service provision in both settings. As soon as his partner heard the news about Phil's HIV-positive diagnosis, her thoughts centred on death, possibly due to a general perception of HIV as a death sentence in her cultural setting, where, in contrast to the UK, there is inadequate access to treatment.

Disclosure to past or present sexual partners raised questions about fidelity and the possibility that one had infected the other. Confronting partner defensiveness about this issue could make disclosure difficult.

Lorna: I called him [husband in country of origin] and asked him, they told me this and this in the hospital [meaning I am HIV-positive]. 'Have you got any idea [of the source of infection]? He [husband] said, "How can you tell me that? How can you say I am sick bla", and dropped the phone? I said, "OK. I will fight with my illness and you fight with yours. But don't call me again." And I don't [call him]! Even if I go home I don't talk to him

(Lorna, 52 years old, HIV-positive for 11 years. Has a partner, Damien who lives independently from her in London, 54 years old, HIV-positive for 7 years. Damien has 4 children from his previous marriage living in country of origin, previous partner died of AIDS related illness in country of origin. Damien's 10 year old son who lives in country of origin and Lorna's 13 years old son who lives in London are known to be HIV-positive)

Lorna wondered if she had been infected by her husband and called to find out what he knew about it. In contrast, Phil, quoted in the previous extract, felt unable to inform his partner that he had been diagnosed with HIV and relied on the support of a counsellor. Whereas Phil's partner did not hang up the phone and was concerned about her husband's prognosis; Lorna's communication ended in acrimony with her husband terminating the phone call and her ending the relationship. Crucially, Lorna's husband had immediately interpreted her disclosure as indicating that he was sick, and has rejected this implication in a way which led to communication breakdown. Other participants also indicated that disclosure of their HIV-positive diagnosis had resulted in the breakdown of sexual relationships.

All of the female participants believed that they had been infected by their current or previous male partners with whom they had had long-term relationships prior to their HIV-positive diagnoses, as illustrated below.

Interviewer: *And why were you so convinced that he had to be?*

Harmony: *Because that was the only partner I had. If I had - was going up and down [unfaithful] - I would say may be I got HIV from someone else.*

Harmony, 48 years old, HIV-positive for 13 years. Has a partner, Robin living with her in London, 45 years old, HIV-positive for 14 years. Harmony has 2 biological children and 4 adopted children from her late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

As illustrated in the literature review in Chapter 1, some of the participants originated from cultural backgrounds that permit polygamy. Men were therefore either culturally free to have, or were suspected of having, multiple partners, whereas the cultural expectation for women is that they will 'faithfully' take care of the children. All six of the women who participated in the study blamed their HIV infection on their husbands' or partners' perceived unfaithfulness. Five of the 11 HIV-positive male participants confirmed that they suspected that they had infected their partners. Such men used adjectives such as 'reckless', 'carefree' and 'invincible' to describe their sexual attitude, and employed phrases such as living 'life in the fast lane' to analogize their previous sexual lives. Of the 11 men with HIV, only one blamed his partner for his HIV infection. He met her after coming to the UK and reported an

accepting attitude towards her being the likely source of his infection, although their relationship had become strained at the time of the study.

Interviewer: How does that make you feel?

Biden: *That's why, at times that's why I just want to give her space ... because in the first place she is the one who put me in this position. But she said sorry you know, and I said ok, I don't mind.*

(Biden, 43 years old, HIV-positive for 11 years, has no children. Separated from partner Melisa, 43 years old, HIV-positive for 13 years, has 1 adult child. Biden and Melisa still visit each other. Melisa's 13 year old son is known to have died of AIDS related illness in the UK)

The relevant woman, Melisa, agreed that she was the probable source of infection, suspecting that she in turn had been infected by her African ex-husband, who had since died. But as the quote above suggests, the participant said he had forgiven her and moved on, perhaps because she had admitted to being the source of infection and was apologetic. However, Melisa indicated during her interview that she could never be certain that it was she who had infected her husband. Both participants pointed out that it was difficult and pointless to try to establish the source of infection. Biden, the husband, was fatalistic about his HIV-positive status, accepting that he was destined to live with it for the rest of his life.

Disclosure to present or previous sexual partners involves consideration of the possibility of transmission from one to the other having taken place. The next subsection discusses disclosure to other relations where this issue was not relevant, but where other sensitivities could make disclosure equally difficult.

3.2.3.2 Confiding in siblings

Four of the 11 HIV-positive men and two of the six women said they had told at least one of their siblings about their HIV diagnosis. The extract below exemplifies the risk of rejection arising from such disclosure.

Interviewer: And at the moment, who knows you are living with HIV?

Damien: *Eeh, my sister.*

Interviewer: Your sister here?

Damien: *Yea. Because by the time when I got the results, I told her together with my brother ... I couldn't hide anything. Because ... I was expecting ... to get support from my brother, my sister. He is here [the brother is in the UK], but the way how he was handling me, he is not my friend now ... my sister is giving me support.*

(Damien, 54 years old, HIV-positive for 7 years, has 4 children in country of origin from previous marriage. Previous partner died of AIDS related illness in country of origin. Has partner, Lorna who lives independently from him in London, 52 years old, HIV-positive for 11 years, has 2 children. Lorna's 13 year old son who lives in London and Damien's 10 year old son who lives in country of origin are known to be HIV-positive)

Damien chose to disclose his infection to his siblings whilst they were visiting him in England. This resulted in rejection from one and support from the other. Damien's account clearly illustrates the risk surrounding HIV status disclosure; where it is difficult to predict with support or rejection. In either case, disclosure is irreversible. Damien could not take back the information and subsequently had to suffer a strained relationship with his brother. Additionally, he then lived with the risk of exposure by his brother, despite Damien's ongoing attempts to conceal his status from their mutual social contacts. Based on his brother's negative reaction to the news, Damien doubted that he would maintain confidentiality. Although Damien's sister was supportive, there was also no guarantee that she would never intentionally or unintentionally expose his status to some of the people from whom Damien was actively striving to conceal his infection. This exemplifies a key challenge for people living with HIV, in that they can never know for certain who might expose their status, or when, and to whom. This issue will be discussed in detail in Chapter 5 which focuses on exposure.

3.2.3.3 Informing the children

Some participants disclosed their HIV-positive status to their children, although others did not because they felt inadequately skilled to do so, or they believed that by concealing the information from the children, some of whom were themselves infected, they were protecting them from harm, as discussed below. The child's age was a key consideration, but most of the affected parents were unclear about what was the 'right' age. This point is discussed further in the next section of this chapter.

Disclosure to children also implied discussion about the parent's sexual history, a cultural taboo for some members of the present study population.

Eight of the 12 men and all of the women who took part in the present study said they had children. Some participants had left their children in their country of origin, and some said that they had children with their partners in the UK, in addition to those they had with previous spouses in their countries of origin. Some of the men were also living with their partner's children from previous relationships. Discussions about HIV status could therefore involve children in their countries of origin, their own children or stepchildren living with them in the UK, or any other children under their care.

For most of the participants, particularly the men, disclosure to children was a daunting task. The findings suggest that disclosure to children was a responsibility left to the women to handle on behalf of their husbands or partners. None of the HIV-positive male participants with children had directly revealed their condition to them. The discussions below are thus based on extracts from the interviews with women. The men who believed their children knew they were living with HIV suspected that their partners or other family members had disclosed the information.

Interviewer: *And have you gotten to tell the children? Any of them know there is HIV in the family?*

Robin: *Yes, yes. The bigger ones [aged 18, 24 and 26 years at the time] knows there is HIV in the family. But the mother is the one who told him. Again it is the mother who does all the speaking. Yea. I have not sat with my son and told him that I am HIV-positive. But the mother ... has told him.*

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

Robin stated that his older children had learned of Robin's HIV status through their mother. The tone of the quotation suggests that Robin did not mind if his older

children knew he had HIV, even though he had not told them himself. Robin claimed that his partner 'does all the speaking'. However, his partner Harmony reported that she did not tell the children about the parents' HIV-positive status. Instead, she took them for counselling services where they were told about HIV in the family by a service-provider. The varying perspectives on and assumptions about HIV disclosure to children illustrated here suggest gender variations among the participants regarding disclosure to children. Whereas the men seemingly found it too difficult to disclose to their children and assumed that the women informed them, some of the women also found it difficult but made direct efforts to let the children know that there was HIV in the family, either by breaking the news themselves or through support services. The women therefore provided a voice for partners who felt unable to reveal their own HIV-positive status to their family members, including their own children.

Interviewer: *And at the moment, who knows that you are living with HIV?*

Millie: *My children*

Interviewer: *Ok. Who told them?*

Millie: *Me*

Interviewer: *Please describe to me how you broke the news.*

Millie: *When I got shingles, I called them [Adult children living in country of origin – aged 30, 29, 26, 25 and 17]. I told them to take the young son to test. Then they asked me, 'Why, Mummy?' I told them [that she was HIV-positive]. Then they tested the young boy, he was fine [HIV-negative]. So I told them you have to be careful, because this disease is a problem.*

(Millie, 54 years old, HIV-positive for 3 years, has 5 adult children in country of origin from previous marriage. Has a partner, Phil who lives independently from her in London, 51 years old, HIV-positive for 9 years. Phil has a wife and 3 children in country of origin. None of the children are known to be HIV-positive)

Like the other women who participated in the study, Millie was the one who ultimately told the children about HIV in the family. This is in contrast to her former husband, who died of AIDS without revealing his illness to her or their children. Similarly, Millie's partner in the UK had not told his own children about his HIV-positive status. Instead, he believed his partner, the children's mother, with whom they lived in his country of origin, would have told them.

The motives for parental disclosure to children varied, although commonly parents wanted their children to understand the cause of their death. This issue has been discussed in the literature review, Chapter 1, and is further highlighted by the extract below. Lorna said that, in case she should die, she wanted her children to know the cause of her death.

Interviewer: *How did you tell them?*

Lorna: My kids, I told the older one [19 years old] what is going on. Because when I got sick, I told them, in case I die, I got this from your daddy.

(Lorna, 52 years old, HIV-positive for 11 years. Has a partner, Damien who lives independently from her in London, 54 years old, HIV-positive for 7 years. Damien has 4 children from his previous marriage living in country of origin, previous partner died of AIDS related illness in country of origin. Damien's 10 year old son who lives in country of origin and Lorna's 13 years old son who lives in London are known to be HIV-positive)

Lorna's disclosure, like Millie's, was triggered by illness. However, Lorna's children were much younger, her eldest daughter being 16 years old when Lorna revealed her illness. Both cases show the determination of the mothers to inform their children about their disease, a trait not so readily found among the men. Additionally, this concern about prognosis suggests that, despite access to effective treatment, people coming from societies where HAART is not readily available still associate HIV with a high risk of mortality. A further interview with Lorna revealed that she had only disclosed her status to her 19-year-old daughter, and not her son. He was also HIV-positive, and was told of his own sero-status by HIV support services. Lorna said she told her daughter about her HIV status because the daughter was very supportive with the housework whenever she was ill. She also wanted to ensure that her daughter was aware of her illness, in case she passed away.

The perception that younger children were not ready and therefore should not be told that their parents had HIV was also shared by some of the male participants, as illustrated below.

Interviewer: *And is your child aware of what is going on in the family?*

Trevor: No. He just knows that sometimes Daddy has got those bad moods. Sometimes Mummy is in those bad moods. Sometimes they shout ... He really doesn't know anything apart from saying Daddy is going to hospital, a thousand times per week ... He is still too young [5 years old]. And even then, I don't think there is need to tell him. Unless when he is really grown up and reach that risky age where he could go and mess up.

(Trevor, 47 years old, HIV-positive for 3 years. Has a partner living with him in London, HIV-negative, not interviewed. Trevor has a 5 year old son, the son is known to be HIV-negative)

The above extract adds a risk dimension to consideration of the right age to tell a child that parents and/or the child are HIV-positive. Trevor suggested that disclosure of parental HIV status to children should take place when they are themselves at risk of 'messing up', implying when they are sexually active and in a position to put themselves at greater risk of HIV infection. However, there is no specific age at which young people start venturing into sexual relationships or other HIV risk factors such as drug use. Waiting for a particular age to disclose parental HIV status, especially if the intention was to deter them, as implied by Trevor above, could mean that the information comes too late. Parents felt uncertainty about setting an appropriate age for disclosure, and were aware that the longer they left it, the greater the risks of infection for their children, and the more likely it was that their own status would be exposed. Older children may discover medications, hear about hospital or clinic visits, become curious and look up information for themselves, all of which increases the risk of exposure of parental HIV status, as discussed in Chapter 5. The next subsection discusses disclosure to friends.

3.2.3.4 Confiding in friends

Friends were another carefully managed group of disclosure recipients because they were considered a possible source of support, but also of potential stigmatization and unwanted exposure. They were also concerned that relationships with friends might break down. Recognising the irreversibility of disclosure, most research participants, other than the four who had 'come out', were hesitant about sharing knowledge of their HIV-positive status. The findings suggest that the participants were most likely to confide in UK-based friends who were themselves

HIV-positive. However, some participants had told selected friends, other than those they knew to be HIV-positive, that they were living with the condition.

Interviewer: *How many friends have you told?*

Luke: *About three of them*

Interviewer: *How did you tell them?*

Luke: *They noticed I am always unwell. I was not the same like before diagnosis. So I had to let them know the truth because they were already supportive so much. I didn't want to lose their support so I decided I tell them so that they know. So I said look here, this is what is happening to me. Told each of them separately when I felt it was ok to open up. But I had no idea what to expect. Luckily the three have not run away yet.*

(Luke, 41 years old, HIV-positive for 11 years. Has separated from partner because of HIV, has no children)

Luke was single at the time of the interview because his partner had left him. He said she had told him that she could not cope with his HIV related-stress and uncertainty about prognosis, because she also had similar problems to deal with and that she did not want to be moving from one house of HIV-stress to another. After the loss of his partner had increased his need for support, Luke had summoned the courage to inform some of his friends he had HIV. He felt that he was fortunate that his friends had remained supportive. Luke had suspected that his friends had been able to tell that he was unwell before he said anything to them, and one reason for him telling them the truth was to avert potential exposure. Luke had successfully assessed the right moment to tell his friends, proceeding with extreme caution. The above extract further illustrates his uncertainty regarding disclosure through his comment that he 'had no idea what to expect'. By disclosing to each friend individually, Luke may have been attempting to manage his uncertainty about potential responses by adopting a step-by-step approach.

Lastly, the findings suggest that socioeconomic and cultural differences between the UK and the participants' countries of origin affected disclosure because HIV meant different things in both cultures as discussed further below. It therefore appeared easier for respondents to disclose their HIV status to friends in the UK than those in the country of origin.

Interviewer: Apart from your friend who took you, is there anybody else you told about the HIV?

Phil: *My wife. It's only my wife and my friends here, not in my country of origin, because of the stigma.*

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of origin from previous marriage. None of the children are known to be HIV-positive)

Phil had only told his friends in the UK and not in his country of origin about his disease because of anticipated stigma. However, individual and contextual factors surrounding disclosure also played a role. Phil's partner Millie came from the same country, and whereas Phil had concealed his HIV-positive status from all of his native country friends, Millie had disclosed hers to some friends in her country of origin. These disclosure patterns are illustrative of a general gender difference among the research participants. Overall, the HIV-positive women were more likely than the men to reveal their condition to at least one friend. This difference may arise from the men's greater concern for exposure, as discussed in Chapter 5. The next section discusses open disclosure of HIV-positive status.

3.2.4 Open disclosure of HIV-positive status

The discussions in the previous subsection are based on individuals who selectively revealed their HIV-positive status. However, four participants had 'come out', eventually deciding to be open about their condition. They were engaged in public speaking, and shared their HIV status with audiences in HIV awareness and prevention forums.

Paul: *People know my status. And I am a positive speaker ... From last year and other years I have been a positive speaker ... To empower other people ... you see. People then start paying attention to you. People accept you ... They understand me. I feel I got hope, I got support. I don't have any discrimination or prejudice, have not experience any, you know, extremes of any stigma ... I speak quite open to people to empower them, to make people understand, and educate the community.*

(Paul, 51 years old, HIV-positive for 11 years, has an adult daughter from previous marriage. Has a partner, HIV-positive [unknown duration], lives in country of origin, has no children. Paul's daughter is known to be HIV-negative)

Paul had lived with HIV for seven years, and was comfortable sharing his experiences of living with the condition. He and the other three activist research participants had chosen to challenge attitudes towards HIV rather than attempt to protect themselves by adopting a strategy of selective disclosure and concealment. Other non-activist participants were more concerned about being stigmatized which limited their ability to freely talk about their HIV status with their social contacts as discussed above.

3.3 The timing of disclosure decisions and their social contexts

The research participants disclosed their HIV status at different stages of living with HIV, and under different circumstances. Apart from the four individuals who had become HIV awareness activists, they had to decide whom to confide in, as discussed above, and when best to disclose their diagnosis. Overall, disclosure to healthcare professionals occurred sooner than disclosure to family members or friends because the participants first confirmed their diagnoses through the healthcare system. Within families, those at risk of infection, such as sexual partners, were likely to be told about the person's HIV infection before parents, siblings or children, as further discussed below. The timing of disclosure also depended on the level of interaction with the disclosure recipients. Those with whom the relevant participants had daily interactions were more likely to notice any physical or behavioural changes than those with whom they rarely interacted, including those in their countries of origin, making concealment more difficult.

Research participants who had not 'come out' made judgements not only about whom to confide in, but also when to tell them. They did so when they felt that the benefits of opening up would outweigh the costs of concealing their HIV status. Some participants had disclosed their status to significant others soon after

diagnosis, whilst others recounted holding back, sometimes for a considerable time, up to five years and more.

3.3.1 Immediate Disclosure

3.3.1.1 Immediate Disclosure to Professionals

Although individuals cannot know for sure that they have acquired HIV before receiving a diagnosis, they may suspect that they have been infected, and must 'disclose' their reasons for seeking testing. As with other serious health conditions, the reactions from those who inform them that they are HIV-positive can have a strong impact on their feelings about acquiring this status, as illustrated by the following quotation.

Interviewer: *Please describe how you found out you had HIV?*

Luke: So the GP [in London] sent me to the hospital. He asked me to go for an HIV test. He explained to me why I needed to do an HIV test. ... So when I went, I was told, 'You are positive' ... That doctor at the hospital, I found him a bit rude. He didn't explain to me nicely what it really meant to be positive nicely ... I went for a second test to confirm I had it [HIV]. Luckily, I met a different doctor who was really nice. He sent me to a health advisor who told me I was not the only one with HIV ... So the health advisor referred me to the support groups. She travelled with me to [named support organisation].

(Luke, 41 years old, HIV-positive for 11 years. Has separated from partner because of HIV, has no children)

Other research participants described feeling unsupported when they were first told that they were HIV-positive. Luke, according to his account, had sought a second diagnosis not because he doubted the first one, but because he had received a negative message about what being HIV-positive would mean. Fortunately, he felt that he had received a more supportive response during the second diagnostic episode. Such first experiences may greatly influence attitudes towards disclosing HIV-positive status, particularly in the crucial first period of living with the disease.

3.3.1.2 Immediate Disclosure within Families

Some of the participants often disclosed their diagnosis to selected family members, including sexual partners and siblings, soon after testing positive. For example, Damien told his partner that he had tested HIV-positive immediately after finding out.

Damien: When I got my results from the hospital, I told her [Damien's partner at the time, who passed away in his country of origin, hereafter referred to as late partner] straight away ... because she was aware that I was in hospital. And I said to her that I am HIV person. So the only advice I give you [the late partner], I know medications are not available there [in his country of origin], you know there are some herbs which they used to sell. Because that was the only thing which they used to sell those herbs in jerry cans [5 litres plastic bottles]. And one had no choice but just to take those herbs to survive. So I told her [late partner], if you get money, try to take that herb. But it couldn't work. And I had no money. It was hard to support her [late partner] with that.

(Damien, 54 years old, HIV-positive for 7 years, has 4 children in country of origin from previous marriage. Previous partner died of AIDS related illness in country of origin. Has partner, Lorna who lives independently from him in London, 52 years old, HIV-positive for 11 years, has 2 children. Lorna's 13 year old son who lives in London and Damien's 10 year old son who lives in country of origin are known to be HIV-positive)

Damien, like many other participants, said he had been in hospital before his diagnosis. He was hospitalized with acute TB and pneumonia in a London hospital just three months after his arrival in the UK. While in hospital, the doctors told him that TB infection was commonly linked to HIV infection, a co-infection more common in Sub-Saharan Africa where he had come from. He was subsequently offered an HIV test, to which he consented, and he tested positive for HIV.

Soon after his HIV-positive diagnosis, Damien revealed his condition to his partner in his country of origin, partly to explain why he had been ill, but also so that she could seek care in case she had been infected. Unfortunately, treatment was not freely available there at the time. In consequence, his partner could not fully benefit from the prompt disclosure designed to help her.

Some participants also disclosed their status to their siblings or parents soon after diagnosis, as illustrated below.

Interviewer: *Please describe how you disclosed your HIV status to your family members*

Lucy: After my husband died and I was very ill. So after I got the test results I just told my sister that this and this is happening to me. And she told my mother and my other sisters. They were very sympathetic and kind of blamed my previous husband but it was too late to blame anyone really.

Interviewer: *Why do you say so?*

Lucy: *Because he was already dead and I was already infected. You can blame all you care but he was not going to wake up and my HIV is not going away. So there is no point blaming.*

(Lucy, 35 years old, HIV-positive for 9 years. Has partner, Robert who lives with her in London, 40 years old, HIV-negative. Their only child, 2 year old daughter living with them in London is known to be HIV-negative)

The above extract suggests that Lucy told her sister about her HIV-positive status soon after she learnt of it. The extract also highlights the link between disclosure and exposure of HIV status because it shows that Lucy's sister revealed the information to the rest of the family members. But Lucy did not protest this exposure because, as she noted, her mother and siblings were very supportive of her. This could be because she had just lost her husband, whom they blamed for infecting her, thereby drawing the family members' sympathy for her and subsequent support.

3.3.2 Disclosure postponement

Some participants took more time to reveal their infection, particularly if they were not actively seeking support services and were asymptomatic. Most of the long-term delayed disclosure is treated as concealment in this thesis because it remained unknown when the relevant participants would reveal their condition to some of the people they were actively concealing it from at the time of the study. Delayed disclosure was particularly common with disclosure recipients not directly involved in the clinical care of the relevant participants and who were unable to detect any signs of their disease. Such individuals included parents, siblings, sexual partners and friends. This suggests that, where, as we have seen, those who were diagnosed while seriously ill were more likely to disclose soon after diagnosis, the more asymptomatic the individuals were, the more likely they were to delay disclosure.

However, such delayed disclosure led to other challenges, such as strained relationships, exemplified in the following quote.

Interviewer: *So, if I get you right. You first tested outside the UK?*

Troy: *Yes. But was uncomfortable* [to disclose his HIV-positive status]. It took me a long time to tell her. And the longer I left it the more difficult it became [to disclose his HIV-positive status]

(Troy, 57 years old, HIV-positive for 12 years, has 5 adult children, 2 living with their mother in England, 3 living in different countries in Africa. Separated from partner because of HIV. None of the children is known to be HIV-positive)

Troy first tested positive before relocating to the UK but he did not tell his partner, partly because he doubted the validity of the initial test result. Troy had also been unable to bring himself to tell his partner that he had HIV. The family, including his partner and two adult children, later relocated to England where Troy tested again and had it confirmed that he was indeed infected. This time, Troy was convinced that the test was reliable, but still did not disclose his status to his partner. Delay made it even more difficult for him to disclose his condition because of the need to explain why he had taken so long to tell her. According to Troy, although he ultimately revealed all the details of his HIV infection and illness, his partner was not sympathetic and was further upset that he had concealed his HIV status for so long. Troy believed that his partner had developed an alcohol problem as a result of learning about his HIV status, because she believed she was also infected and was preparing to die.

Eventually, Troy and his partner separated, attributing the break up to his HIV status. Troy noted that his partner agreed to take an HIV test after their break-up, and found that she was not actually infected. He indicated he was happy that ultimately the secret had come out. His particular challenges were identifying the right time and working out how to disclose his status to his partner, knowing that once the information was out, he would have no option but to deal with the outcome. Ironically, Troy delayed disclosure so as to avoid exposure, rejection, isolation and stigmatization but, in delaying the disclosure for so long, he may have brought about or exacerbated the hostility of her response.

Damien and Troy's examples of disclosure illustrate contrasting contexts of time and risk in managing HIV status disclosure. Damien disclosed immediately and faced fewer negative consequences, although his disclosure did not have the intended effect of reducing the risk of ill health for his partner, because she was in a setting where there was no treatment. In contrast, Troy delayed disclosure, finding himself unable to tell his partner of his infection. Delayed disclosure heightened the risk of exposure. It also resulted in stress from trying to keep a secret, the precluding of possible emotional support, and the risk of onward transmission to sexual partners and, through vertical transmission, to children. It seems that whether the affected participants delayed disclosure or disclosed soon after diagnosis, they faced different risks and each individual took different measures which they deemed appropriate to their perceived risks or benefits.

3.3.3 Deferred disclosure to Children

Delayed disclosure was also common when it came to telling children about HIV in the family. Most of the participants who had told their children about their diagnosis indicated that they delayed disclosure to the children until they considered the children to be old enough to cope with the knowledge.

Interviewer: *Do the children know that parents have HIV?*

Harmony: Yea, my 18 year old knows, but the young one [10 years old] doesn't know. But my sister's children, the elder ones knew [26, 24 years old]. The younger ones [13 and 11 years old] not yet. So I am planning one of these days, to take them to support services ... to tell them [disclose HIV in the family] ... I normally go there. They have counsellors for children

(Harmony, 48 years old, HIV-positive for 13 years. Has a partner, Robin living with her in London, 45 years old, HIV-positive for 14 years. Harmony has 2 biological children and 4 adopted children from her late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

Harmony had adopted four children from her late sister, and had two children of her own. By the time of the interview, two of the six children had moved out of the family home to live on their own. Harmony believed that the younger children had no idea

what was going on in the family because she had only informed the older children about their parent's HIV status after they turned 18.

What was considered to be the most appropriate age for disclosure varied and was influenced by individual family circumstance, as discussed below.

Interviewer: *And because you work in the sector as well, how do you think other parents go about it [disclosing to the children]?*

Dan: Like I said most of them ... it depends on the age. And how they are coping. Some of them [parents] they do it earlier. Because they just can't keep on taking medication around - the children will start being serious [asking] why are you taking this medication? Then they will sit them down and tell them this is ABC. So, it is different ... But they tell you [that] if you have problems with disclosure to your children, then there are people who can help you.

(Dan, 49 years old, HIV-positive for 12 years. Has 2 children in country of origin from previous marriage. Has partner, who lives with him in London, not interviewed. Dan has 3 children in London, one of them a step-daughter from the partner's previous marriage. Dan's 12 year old daughter in country of origin is known to be HIV-positive)

As discussed in the previous section, all of the participants who had children expressed a general belief that children should be told about their parent's HIV status when they were 'old enough'. The extract from Dan here further illustrates the problems caused by the subjective nature of understandings of this age threshold. Although there was no consensus, adolescence seemed to be the preferred age of disclosure to children. Considering that four infected children were born with HIV, the relevant mothers took between eight and 15 years before they told the children about their illness. Delaying disclosure to children increased the risk of exposure, as highlighted by Dan. Variation in the timing of disclosure of HIV status to children may depend not just on their chronological age but also on the parents' assessment of their levels of maturity, knowledge and awareness. Some parents may feel compelled to disclose their disease to children before they judge them to be 'ready', through fear of imminent exposure.

However, as discussed in the previous subsection, some parents, having made the decision to disclose, then found it too difficult to tell their children that they had HIV and relied on support services to tell them about parental HIV, or, in some cases, the child's own HIV-positive status.

Interviewer: How did you manage to tell your son?

Lorna: *I didn't tell him. But he was going to hospital on and off ... cough which was not stopping. He was admitted at ... hospital for three months ... And the nurse told me that he has to go and meet other kids like him [living with HIV]. And I told her I can't tell him and I am not going to tell him. And the lady ... took him to support services ... where they told him. After like two three four months he came and told me, "You know why I am going to [support group]?" ... "That they said I got HIV, I don't know where I got it from ... I said, "No, I think your dad". And he said, "But my dad can't do that because my dad is well"*

Interviewer: How old was he by then?

Lorna: *I think by that time he was 13. I think 12 or something like that.*

(Lorna, 52 years old, HIV-positive for 11 years. Has a partner, Damien who lives independently from her in London, 54 years old, HIV-positive for 7 years. Damien has 4 children from his previous marriage living in country of origin, previous partner died of AIDS related illness in country of origin. Damien's 10 year old son who lives in country of origin and Lorna's 13 years old son who lives in London are known to be HIV-positive)

Lorna, like many other participants, had felt unable to disclose to her son that both she and he himself were infected. She stressed that she didn't know how to go about it and that her son was still too young. She waited for her son to become 'old enough' and then used counselling services to inform him that they were both HIV-positive. Interestingly, the son also delayed 'disclosing' his own status to the mother after he was informed by the HIV support services. Lorna said it took her son three to four months after he was counselled and told he had HIV to discuss his HIV status with her. As the extract depicts, Lorna's son asked about the source of his infection. The question was related to Lorna's sexual life which she probably found difficult to discuss with her son. She tried to exonerate herself from any potential blame for infecting the son by indicating that the source of infection was his father, presumably meaning that his father had infected his mother who had then transmitted the virus to him through pregnancy. However, the son had challenged this explanation, asserting that his father was well, implying that he had not, at that time, realised that the latter was also HIV-positive.

Some participants delayed disclosure to their children until their teens, telling them then because of concern about the risk of HIV transmission after they became sexually active. They believed that, by delaying disclosure, they were protecting younger children from information they could not comprehend or cope with.

Interviewer: Does your son know about the HIV in the family?

Trevor: *He is still too young. And even then, I don't think there is need to tell him. Unless when he is really grown up and reach that risky age where he could go and mess up [engage in unprotected sex].*

Interviewer: Ok. So when he reaches that age you plan to -

Trevor: *Yes, we sit him down and say you know why I was using wheel chairs and crutches and this? I was this! [Implying was HIV-positive] ... It depends on why. Disclosure comes in when there is really need. It is like going home to your son and saying, "You know what, I have AIDS". Just all over a sudden without anything you could shock this kid so badly*

(Trevor, 47 years old, HIV-positive for 3 years. Has a partner living with him in London, HIV-negative, not interviewed. Trevor has a 5 year old son, the son is known to be HIV-negative)

At the time of the interview, Trevor's son was five years old. Trevor believed that even if he had wanted to tell him, his son would not, at that age, have been able to comprehend what it meant to be HIV-positive. He further explained that he would continue to delay disclosure until a perceived need arose. Trevor avoided disclosure to his child to protect him against information which he felt could harm him psychologically. The argument that disclosure ought to happen for a purpose, and not merely for the sake of it, was also expressed by some of the participants in relation to adult disclosure recipients.

One key justification for delaying disclosure to the children was to protect them from harm. However, disclosure to children, especially about their own HIV status, could itself cause distress.

Interviewer: So the child was asking but was not told directly?

Anne: *No, the child was not told ... it took five years for the mother to disclose to the child that you are HIV-positive and that's why you have to keep on taking medication*

Interviewer: Did they tell you how it went after disclosure?

Anne: *The child I think ended up ... He would just start shaking. Because, I think, he was overwhelmed ... He would actually fall on the ground as if he was having a fit ... I think the child was angry that the mother had not told him that this is the condition that I [son] have. That's why you are taking medication. You know children at three are very knowledgeable. They can pick up things. So he was lied to for a very long time.*

{Anne, Black African. Works in London for an organisation that provides emotional and social support services for HIV-positive individuals in England}

Anne's account challenges the view expressed by a number of the research participants that younger children should not be told about HIV in the family, or even about their own infection. Her argument echoes one of the main issues highlighted in this thesis, namely the trade-off between concealment and risk of exposure. She suggests that even very young children may realise that they are HIV-positive despite not being told, and that delaying disclosure may itself have harmful consequences for the child.

3.4 Summary

Apart from four individuals who had become HIV awareness activists and revealed their condition openly, participants engaged in ongoing assessments of the potential benefits and risks of disclosure to determine to whom they should reveal their HIV-positive status, and when. It has been illustrated that HIV status disclosure was crucial for access to treatment and support but sometimes resulted in rejection and stigmatization and increased the risk of participants' positive status being exposed to third parties.

Most participants, other than those who had 'come out', selectively disclosed their sero-status to health and social care workers involved in their care; their peers at HIV support groups; family members and friends. However, disclosure to friends in their countries of origin was usually limited. Those with friends in the UK pointed out that they were drawn mainly from the support groups they accessed, guaranteeing that the recipient would either be HIV-positive themselves, or, if not, sympathetic to those who were. Sexual partners, siblings (especially sisters), and children were, in that order, the family members that respondents were most likely to tell about their HIV status. Mothers were much more likely than fathers to take responsibility for disclosing to children. Participants attempted to gauge the most appropriate age at which to tell their children about parental HIV, and, in some cases, a child's own HIV-positive status. Some reported that they had found it difficult to inform children directly and had therefore relied on support services.

Concealment, that is, selectively withholding information about one's HIV-positive status, is the focus of the next chapter.

CHAPTER FOUR

CONCEALMENT

CHAPTER FOUR.

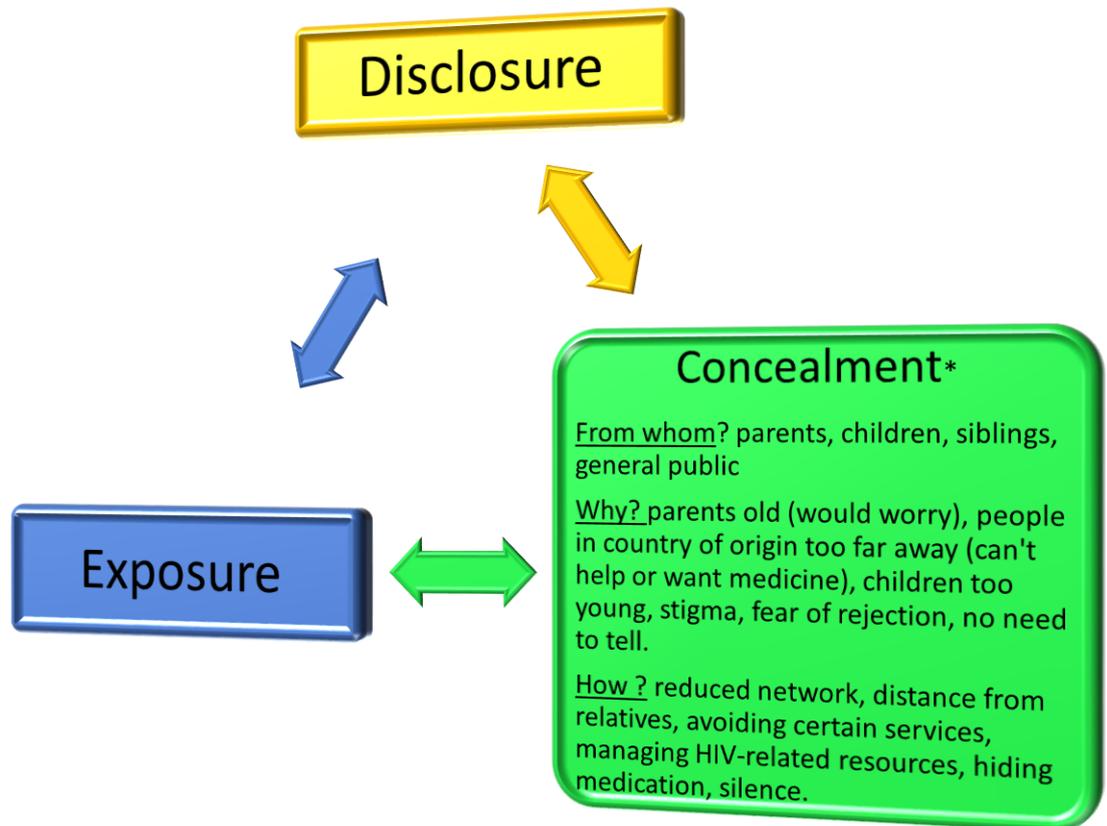
CONCEALMENT OF HIV STATUS

4.1 Introduction

The previous chapter discussed the ongoing dilemma faced by many of the participants regarding why, to whom and when they should reveal their HIV-positive status; and their concerns about losing control over the information, since, once they had disclosed it, there was no guarantee that the disclosure recipients would not then expose the participants' condition, either intentionally or unintentionally, to others. The chapter illustrated that, other than 'default' disclosure to health professionals in order to access HIV-related services, disclosure behaviour varies individually and is restricted by concerns about losing control, rejection and stigmatization; leading most research participants, other than the four who had 'come out', to attempt to selectively conceal their condition.

The majority of the participants tried to conceal their HIV status from selected members of their family and wider social networks. However, in some cases, participants learnt that some of the people from who they had been concealing their status were, in fact, already aware of it, suggesting that these participants had unwittingly lost control over their HIV status information. By attempting to conceal their status from certain individuals, these participants not only forsook potential sources of support, but also faced a constant risk of exposure. The concept of exposure will be explored further in Chapter 5. Some responded to the perceived risk of exposure by disclosing their status whenever they perceived a threat to the confidentiality they were trying to maintain. The linkage described here illustrates the mutual interconnectedness between the three findings chapters, as illustrated in Figure 4.1 below.

Figure 4.1: Multiple relationships between disclosure, concealment and exposure



*The concealment box is expanded to reflect issues relevant to the present chapter. The same issues are explored in different contexts in Chapters 3 and 5.

Overall, HIV-positive status concealment was a major concern for most of the participants. As illustrated in table 4.1 below, 82% of the participants concealed their HIV status, or the partner's HIV status in the case of the HIV-negative man, from their parents. A similar proportion of the participants were also reserved about discussing their HIV status with individuals outside their families of health and social care settings, unlike the four participants who had become HIV awareness activists and were happy to reveal their condition to anyone they interacted with. The table also highlights widespread concealment from children, siblings and friends as will be discussed further in section on social contexts of concealment of HIV status below.

Table 4.1. Reported concealment (N=18.)

Participants' details			The people that the relevant participants concealed their HIV-positive status from									
Participant	Gender	Age	Concealed HIV status	Support groups	Parents	Partner	Brother	Sister	Children	Other family members	Friends	Public audience
Paul	Male	51	Yes	0	0	0	0	0	1	0	0	0
Robin	Male	45	Yes	0	0	0	0	0	1	1	1	0
Troy	Male	57	Yes	0	1	0	1	0	1	0	1	0
Luke	Male	41	Yes	0	1	0	1	0	0	1	1	1
Dan	Male	49	Yes	0	0	0	0	0	1	0	0	0
Damien	Male	52	Yes	0	1	0	1	0	1	0	1	1
Bill	Male	31	Yes	0	1	0	1	0	0	1	1	1
Trevor	Male	47	Yes	0	1	0	0	0	1	0	0	1
Biden	Male	43	Yes	0	1	0	1	0	1	0	1	1
Phill	Male	51	Yes	0	1	0	1	0	1	0	1	1
Tyron	Male	45	Yes	0	1	0	0	0	0	0	1	1
Robert	Male	40	No	N/A	1	0	1	0	0	1	0	1
Millie	Female	54	Yes	0	1	0	1	0	0	0	1	1
Lorna	Female	52	Yes	0	1	0	1	0	1	0	1	1
Rachel	Female	37	Yes	0	1	0	1	1	0	1	1	1
Harmony	Female	48	Yes	0	1	0	1	0	0	0	0	1
Melisa	Female	43	Yes	1	1	0	1	0	0	0	1	1
Lucy	Female	35	Yes	0	0	0	1	0	0	0	0	1
Total	-	-	-	1	14	0	13	1	9	5	12	14

The rest of this chapter is divided into two sections. The first section explores concealment tactics such as hiding HIV-related materials and avoiding contact with certain individuals. Some participants found that the distance between the UK and their countries of origin aided their efforts to keep their diagnosis a secret from family and friends. The first section also provides context-specific analyses on why participants chose to attempt to keep their HIV-positive status secret from selected others. The second section discusses the different social groups from whom the participants concealed their positive diagnosis. The term 'public', as used here, refers to anyone with whom the participants interacted, other than family members and friends.

4.2 Concealment motivations and strategies

This section discusses the ways in which the participants managed information regarding their HIV-positive diagnosis in an attempt to ensure that it did not reach unintended individuals. Participants took advantage of the distance between the UK and their countries of origin to conceal their disease from Africa-based family and friends. They employed other strategies such as: hiding medication and other HIV-related resources; limiting social contacts; choosing carefully which services to access in order to prevent exposure by individuals from their country of origin; using their native language to exclude non-speakers in HIV-related conversations; and silence about HIV within their families.

As outlined above, many family members and friends of the participants resided outside the UK in their countries of origin. Some participants, perhaps relying on distance to facilitate concealment, felt that disclosing to family and friends in their home country would have little benefit to them, but considerable cost in terms of the stress experienced all-round.

Interviewer: *Have you told any other family members?*

Phil: *No. No one knows.*

Interviewer: *Do you mind sharing why you decided not to tell the rest of the family?*

Phil: *I don't know really. I didn't need to tell them. They are out there. They won't be of any help. They will instead just worry and add to my stress while*

they are stressed there. I prefer to tell someone here who can offer support when I need it.

Interviewer: And how comfortable are you that your family [partner and son] are keeping the status secret?

Phil: Yes, I told them, "Keep it as a secret. It is between me and you".

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of origin from previous marriage. None of the children are known to be HIV-positive)

In Phil's view, his family members were 'out there' and could not be of any help, negating the need to tell them. As outlined previously, participants had to rely on individuals they had disclosed to maintain their confidentiality. Phil told his partner and son to keep his secret from the rest of the family, thereby trying to prevent chains of exposure originating in those he had confided in.

The lack of physical contact between the participants in the UK and family and friends in their countries of origin meant that any HIV-related changes in the participants' appearance or behaviour could not be observed. As noted in the literature review (Chapter 1), concealment was therefore easier to maintain between individuals with less regular contact. The impossibility of hiding the visible effects of the disease, particularly in Africa where it was expected, is illustrated below.

*Robin: But when I went back [to country of origin] the second time, they [family members and friends] saw a completely different, opposite, ya! And at that time also ... around 1996 ... the combination therapy had just started during that time. It had not reached Africa by then. So, in Africa, when you reach the stage of ... skinniness as I was [Switching off from English - **ka ngato ne odhero kamano** - when someone was skinny like that], you knew that he was going to die [of AIDS]. And they could not see how I changed [meaning family members and friends could not understand how he regained weight and became 'healthy']*

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related, 3 of the children are adults who live

independently in London. None of the children are known to be HIV-positive)

Robin was one of the few participants who said he had travelled back to his country of origin several times in the 13 years since his immigration to the UK. Most of the other participants had not travelled to their countries of origin due to difficulties with the asylum process. Those who had been granted leave to remain in the UK had yet to find jobs and therefore could not travel freely. Robin said he had been to his country of origin just before he was diagnosed as HIV-positive. At that time he was so skinny that people naturally concluded he was ill. He said that his family in his native country suspected that he had HIV because they noted similar symptoms, such as severe weight loss, in other people suffering from HIV.

Interviewer: *How did you deal with that?*

Robin: *No. I just don't care. In their head they are thinking. Like one my uncles came and saw me and I was just having a hangover. So he came and asked me, "Oh! You don't look very well". ... You know, in my brain I think I know what he is asking me. They [in Africa] won't ask you that you are HIV-positive*

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

According to Robin, he could 'read' his relatives' thoughts regarding his illness through their reactions, but he felt unconcerned. However, after years of medication in England, he went to visit relatives in his country of origin as a changed man. He said his family members and friends were surprised at how he had transformed from the skinny and obviously ill person they had seen previously, to an apparently healthy man. As illustrated in the previous extract, the fact that he had no contact with his relatives during his recovery and returned to see them after a complete physical recovery, meant that he no longer fitted the villagers' perceptions of what an HIV-positive person looked like.

Robin: *They saw the changes, everybody was shocked. What is this? This man again! Uncles are coming, [Interviewee switched from English - eeeh*

dendi ber! dendi ber! Denda ber? Kara denda berni Kara denda ne rach?] - *Your body is good your body is good, my body is good? Was my body bad?]. In other words they thought that I was, HIV-positive and I was soon dying.*

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

The reference to 'good body' in the vernacular, as illustrated above, can be either sarcastic or express genuine surprise. Robin's response, questioning whether his body was bad, suggests that he interpreted the question as sarcasm. His relatives now believed that he must not be HIV-positive because he was apparently healthy and 'normal' once again. As Robin explained, medication was not widely available in his country of origin at the time and his relatives were possibly not yet aware of the potential efficacy of HAART.

The lack of regular contact with family members and friends in their countries of origin enabled some of the respondents to avoid scrutiny and suspicion about their health, as illustrated above. Whenever they visited their countries of origin, mainly looking healthy, their health was judged based on their appearance at the time. But some of the participants used strategies designed to conceal their HIV-positive status from family members and friends in the UK. Their accounts suggest that the most common such strategy was ensuring that HIV-related resources such as medicines and HIV literature were kept away from living rooms and other shared spaces that might be accessed by family members, friends or other visitors.

Interviewer: And for you in your family how do you deal with visitors or friends who visit and may be its medication time. How do you deal with such situations?

Dan: Such situations, we make sure all the materials, [HIV/AIDS materials], we have a lot in the house ... I will just keep them in files in the bedroom. Medication time, you go to your bedroom and take your medication. These days, there are small, even portable, fridges. If you need to keep your

medication in the fridge, you just have a small portable fridge in your bedroom.

Interviewer: *And if there are relatives who might get their way to the bedroom?*

Dan: *To my bedroom?* [Raised voice, implying never]

Interviewer: *hmmm*

Dan: *Ah no!* [Both laugh] ... *But even if they come in still they don't have to know, because I don't just stack the medication on the tables. They are in their closet. Unless someone comes starts ransacking the closet.*

(Dan, 49 years old, HIV-positive for 12 years. Has 2 children in country of origin from previous marriage. Has partner, who lives with him in London, not interviewed. Dan has 3 children in London, one of them a step-daughter from the partner's previous marriage. Dan's 12 year old daughter in country of origin is known to be HIV-positive)

Dan was involved in HIV prevention work with a London-based community organisation. He was part of an outreach workforce who worked in the community to educate and sensitize people about HIV and other STIs. Consequently, he attended numerous seminars and conferences from which he collected HIV related literature. However, he took care to ensure that no HIV-related resources were left lying around the house. By managing any unwanted discovery of HIV related material, he minimised the clues that might expose his HIV. Dan's case highlights the care taken by some participants to conceal their HIV-positive status.

According to one participant, who was also an HIV support worker, there were some cases involving sexual partners who concealed their infection from one other. This worker gave an example of one couple supported by her, both HIV-positive, who managed concealment from one another by each hiding their medication.

Interviewer: *How do they manage things like medication?*

Anne: *They told me that they hide the medication in a secret place.* [Laughs heartily]. *In fact the woman was telling me the medication is kept at a friend's house. Because the friend is also HIV-positive and they met at a support group. That's what she told me. Fortunately for her, the friend lives nearby to her. So she is able to go and have her medication in the morning and in the evening. So that's what they told me.*

Interviewer: *How about the man?*

Anne: *The man said medication is in a secret place in the house [another hearty laugh].*

{Anne, Black African. Works in London for an organisation that provides emotional and social support services for HIV-positive individuals in England}

The above example was an exceptional but interesting illustration of concealment maintenance. In addition to hiding their medication, they accessed different HIV clinics and support services, thereby reducing their risk of exposure to the other. The concealment behaviour of this couple potentially put each of them at risk of cross-infection and drug resistance, because they could re-infect each other with different strains of HIV. There was also the potential for criminal prosecution by either of them in the case of confirmed sexual transmission of HIV. However, the worker reported that, as the couple independently confirmed that they were married to each other, there was no possibility that one could sue the other. This example also highlights the efficacy of HAART in aiding concealment. As long as the said couple remained well, with no major health concerns, they could easily conceal their HIV status from one another.

Some participants said that they used their native language whenever they wanted to exclude children from a discussion about HIV. All the parents interviewed in the present study could speak at least one native language, in addition to English, whereas their children, having been raised in the UK, could only speak English. This was particularly true of the younger ones, from whom the parents were more inclined to conceal their infection.

Robin: *sometimes we discuss about other families, about their medication and things like that. But what happens naturally in my house is that we switch over to Swahili. Yea, we don't do it deliberately, but it just comes naturally ... We switch off!*

Interviewer: *Why would you switch to Swahili?*

Robin: *I don't know! It just happens ...*

Interviewer: *They don't understand Swahili [referring to their children]?*

Robin: *They don't understand Swahili. So we switch off when they are around. When we are talking about somebody else about HIV, we switch off. Even the word HIV we don't use in the house.*

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

Robin was one of the parents who believed that young children were ignorant about HIV, and that concealment would shield them from distress. He was also aware that children could pick up hints about HIV from daily family conversations. By switching to their common native language Robin and Harmony could discuss HIV whilst maintaining concealment.

Another approach used by the participants to maintain concealment was to sustain silence about HIV. Some said that HIV was not a topic of discussion in their families, as illustrated below.

Interviewer: *Are there any of your family members also living with diagnosed HIV?*

Lucy: Not that I know of, but again you can't tell. Just like if I didn't tell them, they wouldn't know.

Robert: That one is very difficult to know. We just treat each other equally. Whether someone has HIV or not is not our focus. Unless someone tells you, you can't tell. Or unless they get really sick then you can start thinking whether they have HIV or not.

(Robert, 40 years old, HIV-negative. Has partner, Lucy living with him in London, 35 years old, HIV-positive for 9 years. Their only child, 2 year old daughter living with them in London is known to be HIV-negative)

Like many other participants in the present study, Robert and Lucy concurred that HIV was rarely discussed within families unless someone became visibly ill. It seems there was a rule of 'don't see, don't ask' among some of the families. Robin offered a positive framing of this reticence, which he presented as promoting equality. As discussed above, the participants were more likely to discuss HIV with other people, including family members, whom they knew to be HIV-positive. Silence about one's HIV-positive status was in consequence more likely to be met with reciprocal silence from others who were also infected and concealing their HIV-positive status.

4.3 The social contexts of concealment

As noted above, four of the participants had become HIV awareness activists. The other 14 participants consciously concealed their diagnosis (or, in the case of the HIV-negative participant, their partner's diagnosis) from certain others. Concealment itself created multiple challenges which could be detrimental to their health, including stress about concealment, fear of exposure and harm to relationships when concealment failed.

The social groups participants did not want to tell about their condition included selected family members, neighbours, fellow church members, workmates, housemates and friends. However, the social categories most commonly mentioned by the participants as people they were least likely to tell were elderly parents and younger children, as discussed below.

4.3.1 Protecting elderly parents

All of the participants' parents were based in their countries of origin, except one whose mother was in England at the time of the study. Of the 17 HIV-positive service users interviewed, only four said that their parents knew they were living with HIV. The rest were keen to conceal their infection, as illustrated below.

Interviewer: *Even your parents don't know?*

Biden: *No, my parents don't know and I can't tell them.*

Interviewer: *Why, if you don't mind?*

Biden: *No no no, I can't tell them. I can't disclose that. That is my own fate. Why should they know? What are they going to do about it?*

(Biden, 43 years old, HIV-positive for 11 years, has no children. Separated from partner Melisa, 43 years old, HIV-positive for 13 years, has 1 adult child. Biden and Melisa still visit each other. Melisa's 13 year old son is known to have died of AIDS related illness in the UK)

Biden's stance suggests that he considered concealment to be preferable unless the individuals concerned were able to offer help. Furthermore, his notion of HIV

being 'my own fate' implies that it was his responsibility to deal with his condition, rather than one which his parents should be burdened with. By concealing his condition from them, he was protecting them from having to share his burden.

The view of HIV as an individual problem was not restricted to those infected with the virus. An HIV-negative man whose partner was HIV-positive also felt that HIV was a very personal problem, and not the concern of the wider family.

Interviewer: *Have you told your side of the family that your partner is living with HIV?*

Robert: No. There is no need. How are they affected? It's our problem, the two of us. There is no need to involve other people. After all what will they do? They are there in Africa, we are here. What will they do? Nothing! So nobody knows in my family, including my parents ... To me there is no point. And you know HIV in Africa is still a death sentence. So telling people would just make it worse. They will start worrying, and all the stigma. So I don't see any point in telling them.

(Robert, 40 years old, HIV-negative. Has partner, Lucy living with him in London, 35 years old, HIV-positive for 9 years. Their only child, 2 year old daughter living with them in London is known to be HIV-negative)

The above extract documents Robert's justification for concealing his HIV-positive partner from his entire family, including his parents. He believed that HIV infection in his household was a personal problem concerning only him and his partner. Like Biden, Robert believed that his family, including his parents, could not help them because they were far away in Africa. However, it emerged from the interview with Lucy, Robert's partner, that her immediate family members, including her mother, knew that she was HIV-positive. She had been diagnosed as HIV-positive while still in her country of origin, and had revealed her status to her family members at that stage. The differences in the communication strategies adopted by the couple might be an indication of gender differences regarding communication about HIV-positive status.

Robert also sought to avoid HIV stigmatization, which he considered to be stronger in Africa. As illustrated in the next extract, one motivation for concealment of HIV status is retaining confidentiality over one's private sexual life. The difficulty of

divulging such personal information to an elderly relative is conveyed in the next quotation.

Interviewer: *And I would probably start with you to discuss how you found out you had HIV.*

Bill: Aaaaah, me. I found out since 2004. I was really sick, and by that time I was living with my aunty [in the UK]. So, you know ... it was not easy to tell her some of the private things I was having ... I was having gonorrhoea, but I was in pain. So, I said, "No, I think I have to speak to my aunt about it". Then I had to tell - it is like this like this. She said, "Ooh!" ... Then she said, "Why don't we go to hospital?"

(Bill, 31 years old, HIV-positive for 7 years. Has partner, Rachel living with him in London, 37 years old, HIV-positive for 8 years. Bill an 18 months old son. The child is known to be HIV- negative)

The extract shows that Bill concealed his illness from his aunt for a while because he wished to retain confidentiality over embarrassing information. But as he was living with her, he may have felt increasingly inclined to reveal his status because he could not have concealed his problem indefinitely. Bill had preferred to talk to his aunt rather than to her husband, perhaps because the social bond between him and her was stronger. The quotation shows that his concern about revealing his HIV-positive status was not justified, since his aunt had responded in a matter-of-fact, practical but supportive way.

As well as being motivated by embarrassment and a sense that distant parents couldn't help, concealment could be fuelled by a desire to protect parents and to avoid being stigmatized. One participant felt that it was difficult to disentangle these two motives.

Rachel: And is it because I am protecting myself or I am protecting somebody else? Not to tell them because they might be affected with the news that you are telling them. Here, ok, you are telling them the truth, but somebody else will be affected by that.

(Rachel, 37 years old, HIV-positive for 8 years. Has a partner, Bill living with her in London, 31 years old, HIV-positive for 7 years. Rachel has an 18 months old son. The child is known to be HIV- negative)

Rachel contrasted to herself the benefit of telling the truth with the harm that disclosure might cause to her parents. Parental age was often mentioned as a factor, giving rise to concern about the impact on them if they were given the 'burden' of knowing that their child was HIV-positive.

Phil: Yes, because of stigma. And if I tell, like, maybe my Mum, the next thing she will be thinking like, "Oh, my son is going to die" ... My mum is now 79, she is too old. The moment you give her that news [about HIV], It is like turning off the switch [killing her]

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of origin from previous marriage. None of the children are known to be HIV-positive)

Phil believed that revealing his HIV status to his elderly mother would cause her excessive stress and even shock her enough to cause her death. This risk concern, along with fear of stigmatization, were major considerations in his decision to conceal his illness from her. As discussed in Chapter 3 on disclosure, Phil was helped by an HIV support worker to tell his partner about his disease as soon as he was diagnosed HIV-positive, through concern that she could have been infected. His partner had then revealed Phil's status to their 25-year-old son who was living with Phil's mother in his country of origin. Phil believed that his partner and son could probably cope better with the information than his mother, whom he said was too old and fragile to deal with the knowledge. Nevertheless, he had felt unable to directly disclose his HIV-positive status to his partner.

Another reason for concealing HIV-positive status from parents was the belief that they held HIV prejudices based on their general stigmatizing and negative attitudes towards HIV, as illustrated below.

Interviewer: *And earlier on you were talking about never telling your parents*

Rachel: Yea. I think I want to keep it [from them] ... because, as I was telling you, I am the last girl in the family. And coming from a very Christian family, you know, and I don't know whether they have [the parents] ... The way I was

telling you about the way we [her family] see somebody like a prostitute like, you know, you are dirty! I don't know if that is how my parents see somebody who is HIV-positive by now, I really don't know. But the reason why I would not like to tell them, is because I think, because of the respect. I think they [the parents] have respected me, that is what I think. And I think they have taken me as somebody with good morals. And I don't want to taint that. I don't want to change that or paint it in another colour.

(Rachel, 37 years old, HIV-positive for 8 years. Has a partner, Bill living with her in London, 31 years old, HIV-positive for 7 years. Rachel has an 18 months old son. The child is known to be HIV- negative)

Rachel is married to an HIV-positive man whom she had met at an HIV support group. She had lived in the UK for 12 years without travelling back to her country of origin because she was caught up in the asylum system. She strongly believed that her parents should not know about her condition, a conviction based on her awareness of her family's attitude towards HIV. Rachel's account illustrates the moralisation of HIV infection, with those infected deemed to be morally deficient, irrespective of how they might have acquired the disease. Consequently, as a woman brought up in a very 'morally upright' Christian family, Rachel believed she was expected to be of impeccable moral standing, as elaborated below.

Rachel: You know all my friends, people from church. And Africa, so to say. I think the way we used to, I don't know now, but the way we used to talk when we hear somebody who is HIV-positive. It is like somebody who has HIV was immoral, and me being in church! In the choir! And being there in front [part of church choir always at the front of the congregation]! And HALELUJAH! [Sarcastic tone]. You know! I don't know whether you get my point there?

Interviewer: Yes

Rachel: Hmm, it is like that was an abomination.

(Rachel, 37 years old, HIV-positive for 8 years. Has a partner, Bill living with her in London, 31 years old, HIV-positive for 7 years. Rachel has an 18 months old son. The child is known to be HIV- negative)

Rachel's decision to conceal her diagnosis from her parents was largely influenced by what she believed were her family's perceptions about HIV as the preserve of the promiscuous and immoral. Further, she feared the potential character judgement

she would face from not only her family, but also her friends and her church mates. Rachel said that, like many other HIV-positive people, she had been faithful to one partner who, in the end, had infected her with a stigmatized condition. She believed that, despite remaining faithful to her previous partner and her current husband, her HIV infection would cast doubt on her morality in the eyes of her parents and her congregation. Rachel therefore decided to conceal her illness in order to avoid the judgemental attitudes she feared she would face from her family and friends, and to preserve not only her image, but also that of the entire family.

However, Rachel also indicated that she was uncertain whether her parents still maintained those stigmatizing attitudes towards HIV, given the recent advances in understanding and treating HIV, since she had not visited her country of origin for over a decade. However, she was adamant that disclosure was a risk she could not take. Rachel, and many other participants who had been away from their families in their countries of origin for several years, preferred to conceal their diagnoses because they were uncertain about their families' perceptions of HIV and, in turn, could not predict the potential reactions to disclosure of family members in their native countries. Disclosure was as such a greater risk to take, hence concealment became the adopted strategy.

Participants tended to put together considerations such as those outlined above. When they believed that the risk of revealing their disease outweighed the potential gains, which they could not ascertain for certain without risking their confidentiality, their decision was to conceal their illness from their parents. This calculative approach was clearly articulated by the participant quoted below.

Interviewer: And why did you decide not to tell your parents?

Tyron: My parents, I said what is the benefits and disadvantages of not telling them? ... And I think disadvantages is gonna be worse than advantages ... They are going to be sick because of you [because of disclosure] and so on. And even they can't change anything! ... What's the benefit of telling them? So I think the disadvantages outweigh advantages.

Interviewer: What are some of the advantages of telling parents?

Tyron: You know things like support, being able to support you financially, physically, emotionally. All these things you can't get them from parents ...

who are living in Africa. If there is something you can do for me, ok I will tell you straight away! But parents, nothing. Unless to stress them.

(Tyron, 45 years old, HIV-positive for more than eight years. Has a partner, who lives in country of origin pending the outcome of her UK visa application, HIV-positive, unknown period of time. Tyron's previous partner died of AIDS related illness in country of origin. Has no children)

This quote from Tyron suggests a calculation of balance between the perceived benefits and costs of disclosure which, in this case led to the choice of concealment. Reluctance to disclose being HIV-positive was compounded by the cultural expectation that they should provide for their parents' financial needs through monetary remittances, as illustrated by the next quotation.

Damien: My papers were just sorted out in October last year [2010]. I came on 4th November 1999 ... Since then, I have not been able to go back home. Because I was not allowed to go back home ... my passport was with Home Office. So I was stuck here ... I was not allowed to work. To renew my passport, even it needs money to go back home. Because I lost so many relatives - uncles, my brothers, neighbours. It needs more than £2000 to go ... at present am looking for a job. So even I can spend another year without going back.

Interviewer: And how has that made you feel?

Damien: Ah, the first three years was a problem to me. But now I am used. Except that when you get a text message from home there that they want money. They expect you to be working! The social service in our country is different from here. When you give them your address that now I am staying in a star hotel. They can say, "Oh, how can you manage to pay this one?" They don't know the service, that it is bed and breakfast.

(Damien, 54 years old, HIV-positive for 7 years, has 4 children in country of origin from previous marriage. Previous partner died of AIDS related illness in country of origin. Has partner, Lorna who lives independently from him in London, 52 years old, HIV-positive for 11 years, has 2 children. Lorna's 13 year old son who lives in London and Damien's 10 year old son who lives in country of origin are known to be HIV-positive)

Managing concealment was challenging because the relevant respondents had to re-tell the same story or reinvent new stories all the time to counter suspicions regarding their health or behaviour.

Since these participants concealed their status from their parents and other relatives, they had to justify why they could not provide the anticipated financial support or travel to attend social functions such as family funerals. Yet such participants could not reveal why, contrary to family expectations, they had been unable to work since coming to the UK. They tried to keep in touch with their families by providing them with contact details such as their residential address but such efforts created further challenges. As Damien explained, it was hard for his relatives to understand how he could afford to live in a hotel but have no money to send to them. The use of modern communication technology enabled participants like Damien to keep in touch through text messages for example, but such communication led to further stress for the participants because they had to keep on inventing justifications for their failure to meet the relative's expectations for support. Thus, concealment of HIV status from relatives in their countries of origin often led to cascades of concealment of the multiple issues faced by the participants, in relation to which they could possibly have received support if they had revealed the truth to their family. The discussion in the next subsection focuses on concealment from children.

4.3.2 Protecting young children

The data from the present study suggest that the presence of HIV in the family was concealed from children predominantly by male members of the theoretical population. Depending on the pattern of infection, concealment could involve the HIV-positive status of one or both parents, and also that of the child. The discussion below demonstrates that concealment from children centred on a perceived lack of need to tell children, and a perceived need to protect children from stress and stigmatization. Often, the affected children were considered too young to comprehend what it means to live with HIV. Some HIV-positive participants found it hard to explain their disease to their children, even if the child was aware that they were unwell from cues such as the long-term use of medication. Parents found it even more challenging to conceal HIV infection from children who were themselves on HAART, being unable to explain to their children why they needed to take

medication, unless they explained to them what was wrong. Concealment thus created suspicion amongst the affected children, and further stress for the parents.

This section on concealment from children is divided into two further subsections, the first of which focuses on concealment of parental HIV, and the second of which explores the issues associated with concealment of a child's HIV-positive status.

4.3.2.1 Concealing parental HIV-positive status from children

Table 4.2 below illustrates that only two out of the 18 study participants did not have children, either biological or adopted. Although the sampling strategy required some families with children, it also allowed for the inclusion of participants without children, on the basis that their experiences and perceptions of families affected by HIV would provide equally important insights.

Table 4.2. Demographic details of children in each family unit represented in the present sample

Participant	Concealment of HIV-positive status	Residence of the participants' children	Child's HIV status
KCP1	Concealment from an adult daughter	Daughter, 27 years old, living independently, in England	HIV-status unknown
KCP2	Concealment from all six children	3 adult step-children independent (2 sons, 26 and 18 years old, 1 daughter 24 years old), 3 young children (2 sons, 12 and 11 years old sons and 10 years old daughter) lives with parents. All in England	Known to be all HIV-negative
KCP2W	Took adult children for disclosure at the HIV support services	Same as above	Same as above
KCP3	Concealment until children were old enough – adults by the time they got to know through their mother	2 Children (son aged 25 and daughter aged 27) living in England with their mother, 3 children, (two sons [from previous marriage] aged 35 and 31 and daughter aged 30) living in Africa	HIV-status unknown
KCP4	Had no children	N/A	N/A
KCP5	Concealment from children	2 Children in Africa (20 year old son, and 12 year old daughter living with HIV. Has 3 children in England (4 year old son, 2 year old daughter and 12 year old step daughter)	12 year old daughter in country of origin is HIV-positive.
KCP6	Concealment from children	2 step-children in England with the partner (19 years old daughter and 13 years old son - HIV positive) and 4 children in Africa (24 years old son, 21 years old daughter, 18 years old son and 10 years old daughter - HIV positive)	10 year old daughter is HIV-positive, 13 year old step son HIV-positive
KCP6W	Disclosure to her daughter, concealment from her son	living with 2 children in England (19 years old daughter and 13 years old son – HIV-positive)	13 year old son HIV-positive
KCP7	Son too young (18 months)	Living with 18 months old son, England	Son HIV-negative
KCP7W	Son too young (18 months)	Living with 18 months old son, England	HIV-negative
KCP8	Concealment from step-children	Step-son died of AIDS related illness (13 year old then), step daughter (23 years old) independent - England	Step-daughter last tested negative
KCP8W	Exposure - daughter knew through her late son who died of AIDS related illness	13 year old son died of AIDS related illness in England, 23 year old daughter, lives independently in England	Daughter last tested negative
KCP9	Son too young (5 years old)	Living with 5 years old son, England	Unknown
KCP10	Exposure - believed his partner told children	3 children (11 years old son, 18 years old daughter and 25 years old son [from another relationship]) living with partner in Africa	Unknown
KCP10W	Disclosure to her children	5 children in Africa (30 years old son, 29 years old daughter, 26 years old son, 25 years old son and 17 years old son) living independently	Negative as per last test
KCP11	Had no children	N/A	N/A
KCP12	Daughter too young (2 year old)	Living with 2 years old daughter in England	HIV-negative
KCP12W	Daughter too young (2 years old)	Same as above	HIV-negative

Other than the two men without children, a third man had no biological children although his partner had children from her previous marriage. The other nine men and all the women therefore had children from their current or previous relationships, or both. Some of the children were living with the participants in England, others were living in the participants' countries of origin, and some were living in other African countries. Some of the 'children' were actually adults in their 20s and 30s at the time of this study.

The term 'adoption' is used in this section only for the purpose of clarity, to indicate non-biological children. Culturally, the participants considered any children under their care as their own. In some cases, the children belonged to their siblings.

Interviewer: Do you have any children?

Robin: *I have two biological children. And eeh, currently I have other children who I am raising up but they are not my children. In other words they are children of the sister of my wife. My wife only has two children, and I also have two children with her. She doesn't have children with any other person.*

Interviewer: so the two of you have the two children?

Robin: *Yes, but the sister died, so we took their four children. So in other words I ended up raising six children. Some of them who have already gone through university and are already settled elsewhere*

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

This extract from Robin's interviews illustrates that the discussions about children in this thesis do not necessarily refer to children in a biological/nuclear family sense, but rather in a broader cultural sense. It also highlights the complex composition of some of the families involved in the present study.

Although the reasons for concealment from children varied, one of the main reasons was the age of the children concerned. As discussed in the previous chapter on disclosure, some of the participants believed that children could be too young to be told about parental HIV.

Interviewer: Does your son know about the HIV in the family?

Trevor: *He is still too young [son was five years old]. And even then, I don't think there is need to tell him. Unless when he is really grown up and reach that risky age where he could go and mess up [possibly suggesting engaging in unprotected sex].*

Interviewer: Ok. So when he reaches that age you plan to...

Trevor: *Yes, we sit him down and say you know why I was using wheel chairs and crutches and this? I was this! [Meaning was infected by HIV] ... It depends on why. Disclosure comes in when there is really need. It is like going home to your son and saying you know what, I have AIDS. Just all over a sudden without anything you could shock this kid so badly*

(Trevor, 47 years old, HIV-positive for 3 years. Has a partner living with him in London, HIV-negative, not interviewed. Trevor has a 5 year old son, the son is known to be HIV-negative)

As illustrated in the extract from the interview with Trevor above, the participants were concerned about defining the appropriate age at which to tell the children of the parents' illness. Trevor considered his five-year-old son to be too young, arguing that disclosure should only be undertaken for a specific reason, on a 'need to know' basis, for instance when the child became sexually active. Trevor explained concealment in terms of trying to protect his son from unnecessary shock. He also considered the risk of exposure as a reason to consider disclosure, noting later in the interview that as his son grows older, he might become more inquisitive and require an explanation for Trevor's use of walking aids. Trevor said he suffered from severe pains on the feet as a result of anti-HIV medications' side effects. He therefore used walking aid to retain his balance while walking.

Some participants believed that children in general would not be mature enough to understand what it means to live with HIV, and that disclosure should be postponed to a future time, when the children would be old enough to comprehend the information.

Robin: *And when you told your daughter or your son that you are having AIDS or HIV, they don't know much the difference between that HIV and AIDS. Because you are not going to tell your child that I have AIDS and you know very well that you really don't have AIDS. You just say HIV. They don't know*

what HIV-positive means and what AIDS mean. Unless you are sick in the hospital, that's my opinion, unless am sick in the hospital, then I tell them my son or my daughter that I have HIV or AIDS. I think that is when it will make an impact. Because when they just seeing you normal, just doing things as you always, they don't see much difference. But at the beginning, they could see a little bit. I think they could see but they wouldn't. They would just say, "Are you sick?" But sickness could just mean normal sickness.

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

Robin argued that it was pointless telling his children that he had AIDS, a term they might understand as referring to a horrible disease. In his view, the children would not understand the difference between HIV and AIDS. This comment highlights a common misunderstanding even among adults about a distinction which is itself by no means clear-cut. However, Robin argued that, in the case of serious illness, it would make more sense to then tell his children that he was HIV-positive because they could then understand that HIV is a major disease. He argued that, while he was looking 'normal' and going about his daily life as usual, the children would not be able to conceptualize what he meant if he were to tell them he had HIV. Robin's perception was based on the assumption that children can only link disease with illness. Disclosure would therefore confuse and upset children who otherwise viewed their parents as healthy individuals.

However, Robin's argument is based on assumptions about children's knowledge about HIV. In the following extract from an interview with Robin's partner Harmony, she challenged the notion that children are ignorant about HIV. She identified a cultural shift amongst UK-raised children who were more inquisitive, and had more access to information than those brought up in Africa. They were growing up in an environment that encouraged more openness about issues like sexuality and HIV infection in the family.

Harmony: *You know ... children in this country will ask a lot of questions. They are so inquisitive, they want to know a lot of things. And sometimes they throw you a question that you don't know even how to answer it ... So especially the men, the elder one, my son. My son was so much concern, asking me if he and the sister have HIV. I told him no, it is only me and your dad. And then he asked me, are you going to be on medication for life. I said, "Yes, until they get a cure. And we have to take these medications to be ok." ... Normally in Africa we used not to ask our parents a lot of questions. Even if we even saw our parents were fighting or arguing ... you will not ask them why were you arguing. Here the child will ask you what was happening ... Sometimes, you have to explain to the child ... You have to get the words to explain that this was happening because of this and that.*

(Harmony, 48 years old, HIV-positive for 13 years. Has a partner, Robin living with her in London, 45 years old, HIV-positive for 14 years. Harmony has 2 biological children and 4 adopted children from her late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

In this particular family, Robin believed that his partner Harmony had told all the children about HIV in the family, whereas Harmony, like many other parents included in the study, said that she had not, in fact, told the younger children. Robin indicated that he found the prospect of revealing this information particularly challenging because of the composition of his family and the gender of his children. Robin felt that it was culturally inappropriate to discuss sexual issues with his step-daughter, one of his four adopted children from his late sister-in-law. These differences in awareness and concealment within one family illustrate the difficulty in managing information about HIV status. Robin seemed to have lost control over who knew about his infection, thereby increasing his risk of exposure. Harmony, on the other hand, had not told the younger children about either her own or her husband's HIV infection and risked unwitting exposure by her husband, who assumed they already knew. The older children could also unintentionally expose their parents to the younger ones who had not been told. Thus, concealment from the younger children led to confusion about who had discussed what with which children. This confusion led to erroneous assumptions being made about the children's awareness of HIV in the family. This complex triangular scenario

highlights the interconnection between the categories of disclosure, concealment and exposure represented in the three findings chapters.

Another explanation given for concealment involved the operation of a culturally-informed taboo against parents discussing sexual matters – and, by implication, HIV transmission - with their children.

Robin: And there is a cultural barrier which puts me off [talking to his children about the parents' HIV-positive status]. I just find it very difficult as if someone has tied my mouth. In fact I find it very, very difficult just to discuss about sex and things with a child you know. It doesn't work out to me. And ... the bigger daughter who is not mine, but who is already a grown up. To discuss sex with her and she is not my personal child. To discuss issues about sex and things like that, it just doesn't work out for me [laughs].

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

The above excerpt suggests that, for Robin, discussing parental HIV entailed discussing his sexual history with his child, and dwelling on, or at least implying, promiscuity. Robin felt that he could not discuss his HIV status with his daughter, not only because of her gender, but also because she was not his biological daughter. This connection with family composition was highlighted by the reported concealment of step-parents' HIV status, especially by men, as illustrated in Table 4.2 above. Concealment averted the need to provide a sexual history narrative, or at least to imply one, to one's parents or children, a challenge many participants found difficult to deal with. The next subsection discusses concealment of the children's own HIV status by their parents.

4.3.2.2 Concealing children's own HIV status from them

Three of the families involved in the present study reported that they had children who were HIV-positive but were unaware of it. In one of the families, a 13-year-old

child had died of AIDS-related illness prior to the study. He had been diagnosed five years before his parents had informed him that he was living with HIV. In the second family, the man had a 12-year-old HIV-positive daughter living with his partner in his country of origin. As far as the father was aware, his daughter did not know that she was HIV-positive, despite the fact that she was taking medication. Similarly, the third family had two children living with HIV. The man had a 10-year-old son living with HIV in his country of origin and his partner had a 13-year-old son living with HIV in the UK. Both children were from the couple's previous relationships. The 13-year-old boy in the UK had been told about his infection, although not by his parents, as discussed under disclosure in Chapter 3; whereas the 10-year-old boy in the country of origin had not been told that he was HIV-positive, as far as the father was aware.

Differences in HIV prognosis and the availability of medication between the UK and Africa might influence whether or not parents choose to disclose or conceal HIV from their infected children. However, the parents concerned cited their children's age as the main reason for concealment of the children's HIV-positive status.

Interviewer: *And they children, you just said they are still young, so they don't know about it?*

Dan: *No. Not at all*

Interviewer: *How about the big ones?*

Dan: *The big ones [raised tone], the first-born is now mature [20 years old son – living in country of origin]. I have not had a chance to talk to him and discuss it with him. But the other one who is positive [12 years old daughter – living in country of origin], she is taking her medication. Am always talking to her. They have never told her directly why she is taking all those medications. But she is about to join secondary school. So she is working it out with the counsellor where they get her medication ... to make sure that she knows all the conditions and how she is going to cope with her teenage age. Because now she is 12 and she is going to be 13.*

(Dan, 49 years old, HIV-positive for 12 years. Has 2 children in country of origin from previous marriage. Has partner, who lives with him in London, not interviewed. Dan has 3 children in London, one of them a step-daughter from the partner's previous marriage. Dan's 12 year old daughter in country of origin is known to be HIV-positive)

This extract illustrates that age was a major consideration in the parents' concealment of their children's own HIV diagnoses, as was the case with the concealment of parental diagnoses from the children. To his knowledge at the time of the interview, Dan's daughter had not been told that she was HIV-positive. Her father felt she was still too young. However, this situation was about to change with his daughter becoming a teenager and about to start secondary school. According to Dan, disclosure would prepare his daughter to cope with her teenage years. As discussed in Chapter 3, on disclosure, informing children about HIV in their teens was meant to educate them about the condition and its causes prior to them becoming sexually active, in order to minimise the risk of them becoming infected. Dan expected the family to rely on counsellors to inform his daughter about her condition. This highlights a common challenge for parents who frequently felt incapable of disclosing their or their child's HIV-positive status to them, even when they had decided that it was time to do so. The extract also illustrates that the use of professional counsellors as intermediaries to assist with disclosure to children was an important strategy for some of the participants. In this way, parents were relieved of the burden of having to discuss with their children their sexual past.

Some participants living with their children in the UK also relied on counselling services to reveal the HIV-positive status of the child or parents, as illustrated below. Their African cultural background perhaps made it particularly difficult for them to communicate such personal information directly, as illustrated below.

Interviewer: *How did you manage to tell your son?*

Lorna: I didn't tell him. But he was going to hospital on and off ... He was admitted at ... hospital for three months. And when he came back home, he started the medication. And the nurse told me that he has to go and meet other kids like him [meaning with HIV]. And I told the nurse I can't tell him and I am not going to tell him. And the lady came with a cab, and she took him to Body & Soul. That is where they told him. After like two three four months he came and told me, "You know why I am going to Body and Soul?" [Sarcastic laugh to express sadness, followed by long pause]. "That they said I got HIV. I don't know where I got it from ... hospital or what?" And I said, "No, I think your dad". And he said, "But my dad can't do that because my dad is well" ... I said, "No, but your dad is not well".

Interviewer: *How old was he by then?*

Lorna: *I think by that time he was 13, I think, 12 or something like that.*
[Sounding sad]

(Lorna, 52 years old, HIV-positive for 11 years. Has a partner, Damien who lives independently from her in London, 54 years old, HIV-positive for 7 years. Damien has 4 children from his previous marriage living in country of origin, previous partner died of AIDS related illness in country of origin. Damien's 10 year old son who lives in country of origin and Lorna's 13 years old son who lives in London are known to be HIV-positive)

The above excerpt further demonstrates that some parents found the idea of disclosure so challenging that they opted for concealment. Lorna reported that the health professional tried to persuade her to tell her son he was infected but she was adamant that she could not do so, partly because she felt he was too young and also because she simply found it too difficult to tell him. Lorna's particular difficulty in disclosing to her son that he was HIV-positive was possibly related to the transmission route. Lorna told him that the infection had come from his father, but without explaining the details of sexual transmission. Lorna attempted to avoid blame by telling her son that his father had infected him, in a way depicting herself as a victim as well since, by implication, the father had also infected her.

When Lorna said that he had been infected by his father, he argued that his father was 'well'. He thus equated the absence of visible illness with the absence of disease, not unreasonably, since he had not received any previous intimations that anything was amiss. The extract also highlights the kinds of questions raised by children that some parents tried to avoid. In this way, concealment of HIV status from children was used as a means of dodging awkward and culturally taboo discussions about parental sexual history. The next subsection considers concealment from friends.

4.3.3 Concealment from friends

As discussed in the literature review in Chapter 1, friends and family form an important social support network that can enhance the life quality of people living with diagnosed HIV. However, the present study findings indicate that the research

participants rarely disclosed their condition to their friends, particularly those living in their countries of origin. The findings also indicate that most of their friends in the UK were individuals they had met at HIV support groups, thereby negating the need to either disclose or conceal HIV status.

Twelve of the 17 HIV-positive participants had not disclosed their status to friends, as illustrated below. A common reason given for such concealment was the perceived inclination of Africans to 'gossip' about HIV, thereby increasing the risk of unwanted exposure, as illustrated below.

Interviewer: And have you told anybody else apart from your parents?

Bill: No, no, no! Because most of the friends even if we meet, apart from the people whom I know, I tell them, you know, it is like this, like this. But they are those people who are like in my situation [HIV-positive]. But other people who I don't know [unknown HIV status], I can't disclose. Because we are different people. Because you can't trust anybody. They will tell you, "Oh this one is like this like this, this one is like this like this" [they will gossip].

(Bill, 31 years old, HIV-positive for 7 years. Has partner, Rachel living with him in London, 37 years old, HIV-positive for 8 years. Bill an 18 months old son. The child is known to be HIV- negative)

As the literature review indicated, concealment from friends whose HIV status is unknown is a common choice for people living with the condition. As with disclosure, participants seemed to base decisions regarding concealment from friends on informal cost benefit analysis, as illustrated bellow.

Interviewer: And how do you think HIV has affected your life within your family with your husband, with your child?

Rachel: It has denied me freedom. [Laughs]

Interviewer: What kind of freedom?

Rachel: It has denied me freedom because, ah, sometimes you feel you want to go and visit people. And I am one person we like socialising, visiting or people coming to visit me. But I have to limit that, even if, like now, like here, I have one friend who wants to come and visit us. But we have to plan ourselves very well, before she comes. If it is medication, medicine cabinet we have maybe to lock it out or do something, because we don't want her to know.

(Rachel, 37 years old, HIV-positive for 8 years. Has a partner, Bill living with her in London, 31 years old, HIV-positive for 7 years. Rachel has an 18 months old son. The child is known to be HIV- negative)

Rachel suggested that concealment of her condition from friends had curtailed her freedom and constrained her socialising. Rachel and her husband had to meticulously plan and manage any social encounters in order to try to avoid leakage of information regarding their HIV-positive status. However, Rachel accepted such restraints in order to obtain the benefits, as she saw them, of likely confidentiality.

Given that only a few participants had disclosed their condition to friends who were not HIV-positive, it was interesting to explore the factors influencing concealment. The participant quoted below assessed the risks arising from disclosure on a case-by-case basis in order to decide whom to tell, and from whom they should conceal, their HIV-positive status.

Interviewer: *And among your friends how do you manage to keep it to yourself?*

Damien: *My friends?*

Interviewer: *Hmm*

Damien: *You know ... at times let's say you can bring this conversation on the table [about HIV]. You can hear each and every person's views. Or now you can judge that one is lacking information on HIV, you cannot [not disclose to them] oh this one, he is very ok [can disclose]. Yea, not all people they know because they don't know how it is spread. If they see, let's say, a leaflet with HIV, they just drop it. No need to read!*

(Damien, 54 years old, HIV-positive for 7 years, has 4 children in country of origin from previous marriage. Previous partner died of AIDS related illness in country of origin. Has partner, Lorna who lives independently from him in London, 52 years old, HIV-positive for 11 years, has 2 children. Lorna's 13 year old son who lives in London and Damien's 10 year old son who lives in country of origin are known to be HIV-positive)

Damien described his strategy of vetting which of his friends he could risk confiding in and who he needed to conceal his diagnosis from. By initiating a generalised discussion about HIV, he was able to gauge his friends' attitudes towards the condition and to assess their likely reactions to disclosure. He would avoid disclosing to people whose responses in a generalised conversation suggested that

they were ignorant about HIV because they did not want to know about the condition. Damien's account of his decision-making strategy is particularly interesting because it suggests that he was trying to find a way round the 'inductive prevention paradox' (Heyman et al., 2013) that those who conceal their HIV-positive status from particular others cannot know for certain how they would react if they knew about it.

Some participants concealed their HIV-positive status because they were convinced that confidentiality would inevitably be compromised by others as a consequence of the propensity to gossip which they saw as an attribute of African culture.

Interviewer: *How about your friends?*

Melisa: *No, they don't know.*

Interviewer: *Ok, is that something you decided they are not going to know?*

Melisa: *Yes!*

Interviewer: *Any reason if I may ask?*

Melisa: *Yea ... once they know you have got HIV, you will be the story. When they are, like, in a place for drinking, all the story they will bring about [talk about] is about you. They will be saying, "Oh you know so and so, you know, she has HIV, she is going to die". It will just be story ... so that's why I don't tell anybody. I just keep it by myself and my partner.*

(Melisa, 43 years old, HIV-positive for 13 years, has adult daughter. Separated from partner, Biden, 43 years old, HIV-positive for 11 years, has no child. Biden and Melisa still visit each other. Melisa's 13 year old son is known to have died of AIDS related illness in the UK)

Melisa's primary reason for concealment was to avoid stigmatization by friends and members of their social networks. For another informant, concealment from the wider world had become central to his way of coping with HIV.

Interviewer: *Is there anything else you would like to say?*

Trevor: *No ... It [HIV] is not a death sentence as it used to be. But it leads to a very, very painful time that someone that is not positive will never understand ... But the moment you get it, is when you realise the troubles and the pain of it ... I look at my friends when they are laughing and jumping and playing, and I laugh when they are doing that. But they don't know what am going through, you see. They don't know what I am going through.*

Interviewer: *And how do you feel when you reflect on that?*

Trevor: Of course, at times ... I say "Jesus, why, why did this have to be?" But after some time you say, anyway, "It is done. What can I do? ... Take your antivirals, and be yourself, look nice, look good, you don't have to tell everybody" ... So, that is what it is.

(Trevor, 47 years old, HIV-positive for 3 years. Has a partner living with him in London, HIV-negative, not interviewed. Trevor has a 5 year old son, the son is known to be HIV-negative)

Although Trevor accepted the prevailing view that HIV is no longer a death sentence in developed countries, he considered that there was more to living with HIV than just taking medication. He had opted to manage information about his condition through widespread concealment. The price he paid for adopting such a strategy was that he had to maintain a false persona and live with a fissure between what he was experiencing and the image of himself that he presented to others.

4.4 Summary

This chapter provides an analysis of concealment of HIV-positive status as an option used by many of the present research participants. Whereas a few of the HIV-positive participants opted to reveal their condition widely, a majority selectively concealed their HIV status from some of their family members and friends. These individuals weighed the potential consequences of disclosure and concealment of their status. Those who opted for concealment seemingly attached more value to confidentiality and control over the flow of information, than to the potential benefits of disclosure, such as access to social support. As documented in the overview to the three findings chapters, more men than women concealed their condition from at least some others, particularly children. It was also shown that HIV-positive individuals were more likely to conceal their condition from male than female family members.

Concealment of HIV-positive status as a communication strategy served multiple functions for those who adopted it with selected others. It was meant to exclude from the HIV-status-information loop those who could not be trusted to maintain

confidentiality; to protect those perceived to be too vulnerable to handle the shocking news; and to exclude those who were unlikely to provide social support. Concealment from parents and children was intended to protect them from perceived risks such as stress and stigmatization. Some participants felt that their parents were too old to deal with the news of HIV diagnosis, and that children were too young to comprehend what it means to be HIV-positive. Children could also be viewed as a potential source of exposure to others. Physical separation facilitated concealment from friends and family in Africa, as did the invisibility of the disease with respect to concealment from others in the UK. The 17 HIV-positive participants were able to effectively conceal their HIV status until they perceived a need to reveal it or until it was exposed, which is the topic of the next chapter.

CHAPTER FIVE.

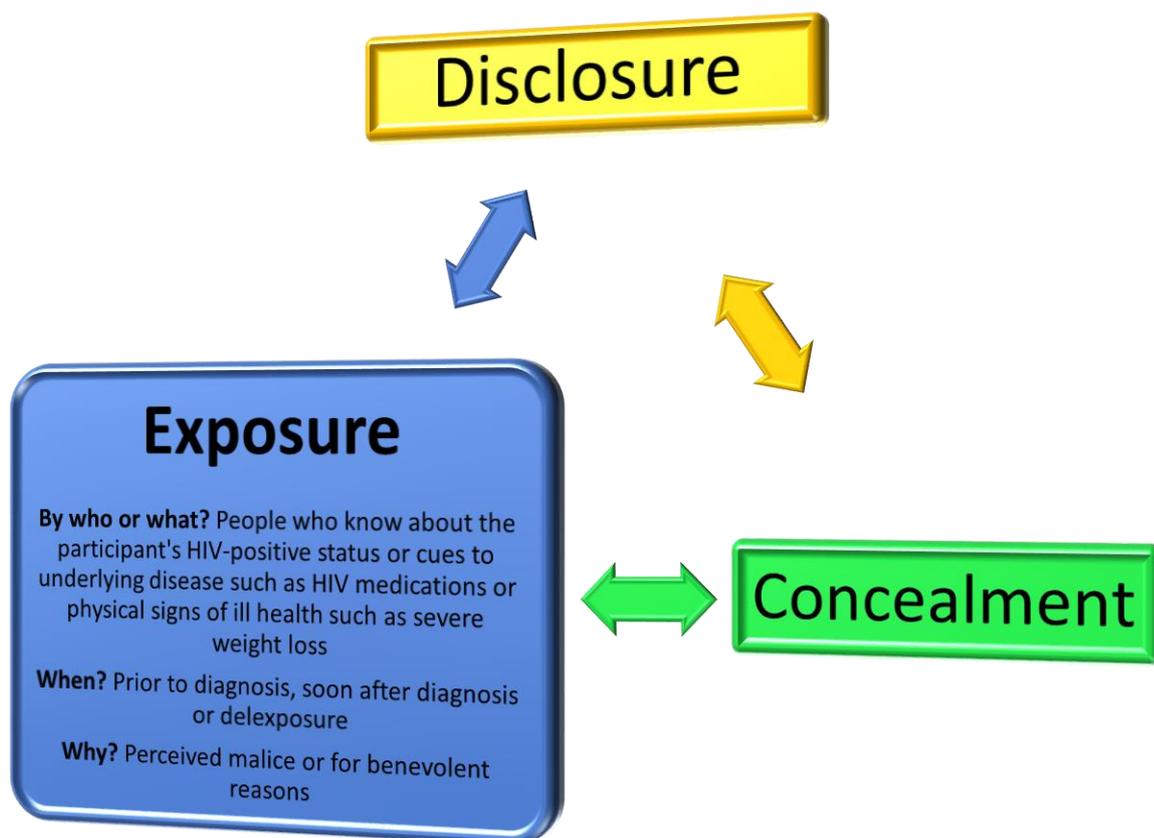
EXPOSURE

CHAPTER FIVE. EXPOSURE OF HIV-POSITIVE STATUS

5.1 Introduction

The two previous findings chapters focused on the dilemma faced by some of the participants regarding whether to reveal or to conceal their positive sero-status to family and friends. As a consequence of this dilemma, the relevant participants selectively revealed their HIV status to some individuals whilst concealing it from others. As illustrated through the model of the participants' decision making process (Figure 0.1 in the Introduction to the thesis), four participants had opted to reveal their HIV status openly, whilst the remaining 14 were selective about disclosing and concealing their HIV infection. However, attempts at concealment were not always successful. The term 'exposure', as defined in the Introduction to the thesis, refers to the unwanted transmission to others of a person's HIV status. Figure 5.1 below highlights the link between the present chapter and the previous chapters on disclosure and concealment of HIV status. The participants' narratives showed that exposure of HIV-positive status was a consequence of and the reason for both disclosure and concealment. Thus, affected individuals avoided exposure by concealing their status, while at the same time risking the exposure that prevented some from revealing their condition in the first place

Figure 5.1: Multiple relationships between disclosure, concealment and exposure.



*The exposure box is expanded to reflect issues relevant to the present chapter. The same issues are explored in different contexts in Chapters 3 and 4.

This chapter addresses the risks associated with the unwanted revelation of the participants' sero-status. Exposure could occur in two ways, either through a second party communicating intentionally or unintentionally to third parties, or through cues 'given off' (Goffman, 1959) such as the discovery of HIV medications or observation of physical changes like weight loss. The following discussion also illustrates that, in some cases, HIV-positive individuals are left unsure about precisely who knows

about their condition. In other cases, exposure was transparent to all. However it was not easy for the concerned participants to verify uncertainty about possible exposure without further risking their confidentiality. Uncertainty about exposure could arise in relation to both the sources and the recipients of information about their HIV-positive status.

This chapter will also discuss the measures deployed by some of the participants in their attempts to guard against exposure. As suggested in Chapter 3, the 13 HIV-positive participants who were concerned about exposure carefully selected and confided in a limited number of people, based on their individual need, trusting that the selected confidants would maintain confidentiality. Some of these participants also reduced their social contacts, while others even avoided particular HIV-related services. One participant who didn't want to reveal his condition said that he had avoided several dental services until he realised that disclosure was a prerequisite for registration to access a dentist. Fearing exposure, one participant completely avoided HIV support groups. However, despite such efforts to control the flow of information regarding their HIV-positive status, exposure was still bound to occur, as illustrated in Table 5.1 below. Using tabulated quantitative data, the table summarises the participants' accounts of their experiences of exposure, and illustrates that 72% believed their sero-status had been exposed at some point in their life with HIV. In terms of gender, 83% of the male participants and 50% of the female participants stated that their HIV status had been exposed to at least one other by the time they took part in this study.

Table 5.1. Reported exposure and the perceived exposers (N=18. 13 reported exposure, 5 did not discuss exposure)

Participants' details				Who or what exposed the participants' HIV-positive status							
Participant	Gender	Age	Exposed	Parents	Partner	Brother	Sister	Friends	Clinician	Medication	Physical changes
Paul	Male	51	Yes	1	0	1	0	0	0	0	0
Robin	Male	45	Yes	1	1	1	0	0	0	0	1
Troy	Male	57	Yes	0	1	0	0	0	0	1	0
Luke	Male	41	Yes	0	0	0	0	0	0	0	1
Dan	Male	49	Yes	0	0	0	1	0	0	0	0
Damien	Male	52	Yes	0	0	0	0	0	0	0	1
Trevor	Male	31	Yes	0	0	0	0	0	1	0	0
Biden	Male	47	Yes	0	1	0	0	0	0	0	0
Phill	Male	43	Yes	0	1	0	0	0	0	0	0
Tyron	Male	51	Yes	0	0	0	0	1	1	0	0
Lorna	Female	45	Yes	0	0	0	0	0	0	1	0
Rachel	Female	37	Yes	0	0	0	0	0	0	0	1
Millie	Female	54	Yes	0	0	0	0	1	0	0	1
Bill	Male	31	Not mentioned	0	0	0	0	0	0	0	0
Robert	Male	40	Not mentioned	0	0	0	0	0	0	0	0
Harmony	Female	48	Not mentioned	0	0	0	0	0	0	0	0
Melisa	Female	43	Not mentioned	0	0	0	0	0	0	0	0
Lucy	Female	35	Not mentioned	0	0	0	0	0	0	0	0
Total	-	-	-	2	4	2	1	2	2	2	4

The table also includes the four participants who had transitioned into HIV awareness activists by the time of the study. The reported episodes of exposure were judged as unwanted because they occurred without the concerned participants' consent. As outlined above, a higher proportion of men than women reported exposure, suggesting a gender difference in communication about HIV-positive status. It was shown in Chapter 4 that men were more likely to conceal their HIV status than women. In doing so they increased their perceived risk of exposure. It was also illustrated that men were more likely than women to assume that their partners had revealed their HIV status. This difference may reflect cultural

stereotypes about gender rather than underlying variations in communicative behaviour.

Five of the 18 participants did not discuss exposure during the initial interviews, as it had not at that time been identified as a theme and had not emerged as a key concern for these respondents. However, when exposure emerged as a key category, the researcher contacted the five participants by phone to explore their views on this issue.

This chapter is divided into five main sections, including this introduction. The second section focuses on the social contexts of exposure, and the third discusses how exposure can occur. The fourth section analyses exposure timing, outlining when participants believed their HIV status had been exposed. The fifth section analyses how participants believed that exposure to have occurred, and illustrates the uncertainty in some cases about whether it had actually happened. Based on their interpretations of the perceived exposers' intentions, the affected participants could read malice or benevolence into their status exposure. However, some participants' attitudes towards exposure changed over time. These participants no longer seemed concerned about the specific exposure incidents that they reported having experienced, suggesting that the impact of exposure might vary with time. The next section considers the social contexts of exposure.

5.2 The social contexts of exposure

This section discusses the affected participants' social relationships with perceived exposers. These were mostly close social contacts who were involved in some way in participants' daily lives. A majority of the participants who believed they had been exposed suspected their family members. Four of the male participants believed they had been exposed by their wives or partners. As illustrated in Table 5.1 above, there were 11 counts of exposure by immediate family members, compared with nine counts of exposure by non-family members. One participant believed he had been exposed by a friend, and another by her housemate. There was one case involving a male participant who believed that clinicians at a London hospital, where

he was admitted for mental health concerns and subsequently diagnosed positive for HIV, had exposed his sero-status to his partner. Interestingly, none of the female participants, all of whom were HIV-positive, reported exposure by their partners. As discussed in Chapter 4 on concealment, men were more likely than women to conceal their own HIV-positive status. They may have shown similar reticence about discussing their partner's condition. The analysis of HIV disclosure in Chapter 3 demonstrated that women tend to be the prime communicators in the family, sometimes acting on behalf of their partners. It is possible that, because of this gender difference, men who suspected exposure tended to assume that their partners had been the ones who had exposed them. However, interviews involving partners sometimes revealed conflicting accounts, with some of the women suggesting that they had never discussed their partner's HIV status with third parties, as illustrated below. It is possible that some of the perceived incidents of exposure attributed to the women either did not occur or were unintended, such as in cases where the woman disclosed her own infection, and the disclosure recipient subsequently inferred her partner's infection.

Apart from close family members and friends, one case of exposure involving UK clinicians was also reported. The example is discussed in this section because generally, health professionals are ethically bound regarding their patients' confidentiality, unless they believe that maintaining such confidentiality would put others at risk of infection. However the participant quoted below believed that he had been exposed by the very people whom he felt had a duty to maintain his confidentiality. The participant, Trevor, said that he had been hospitalised for several months, initially diagnosed with mental health problems and subsequently diagnosed HIV-positive while still in hospital. Trevor indicated that he had found it difficult to tell his partner that he had tested positive for HIV. However, by the time he did feel ready, he learnt that the clinicians looking after him had already told his partner without his consent.

Interviewer: *How did you disclose to her [partner]?*

Trevor: That is another very complicated story. Because I feel there was not much help. It was so painful and took a long time. You know like tossing around about what to say and what not to say ... if the doctors have realised you are in a relationship, you have a wife, you have a son ... But if after

struggling so much, and you say, "I want to speak to my wife, I want to see my son". And then they realise you may say something. Then somebody comes in and then rushes to tell your wife without even telling you first.

Interviewer: Ok

Trevor: This is not right, you see. I think you talk to this person and say, "You know what, I think, why not discuss this one with your wife?" But you don't speak to somebody's partner without them. Because you create friction, which at times could break them up permanently ... I would think you talk to, you ask this guy, however sick.

Interviewer: So you are telling me they told her without your consent?

Trevor: They [the hospital team in a London hospital] rushed into telling her [Trevor's partner]. You see. They [the hospital team] should have first told me, that you know what, let's discuss this with your wife.

(Trevor, 47 years old, HIV-positive for 3 years. Has a partner living with him in London, HIV-negative, not interviewed. Trevor has a 5 year old son, the son is known to be HIV-negative)

Trevor believed his HIV-positive status was exposed to his partner by the health professionals involved in diagnosing his condition. He was adamant the exposure had been wrong, irrespective of how ill he was at the time. Trevor believed that this exposure had nearly cost him his marriage. Although Trevor did not state why the health professionals concerned had acted in this way, their motive may have been to protect his partner from the risk of infection.

Analysis of the data also revealed variations in responses by affected participants towards their perceived exposers. Those who were uncertain about whether exposure had occurred and who might have exposed them were likely to maintain their usual relations with the perceived exposers as illustrated below.

Paul: The family, I think two of my brothers, I think they [family members] know. But I have not told my daughter directly but I am sure she knows from the family. I have not spoken to her directly about my status but the family knows ... As I said, eehh, they have understood my situation and they are supportive. Now we live as if I don't have HIV actually, [laugh], with the family. On Sunday I was with them there [Laugh]. Eat with them. Eeh. You see. It has made my, you know managing the virus easy because you see, if I had any difficulty with my family because of my HIV status, it would have affected me very badly. Maybe I would not be the way you see me now?

[Laugh] ... *So the first thing is the family support, which I have got. Hmmm. It applies to anyone with HIV. If you don't have family support, it is very hard.*

(Paul, 51 years old, HIV-positive for 11 years, has an adult daughter from previous marriage. Has a partner, HIV-positive [unknown duration], lives in country of origin, has no children. Paul's daughter is known to be HIV-negative)

The extract illustrates that Paul was uncertain about how many of his family members knew about his disease because, although he had not told some of them personally, he nevertheless believed they knew he had HIV. However, he also alluded to the fact that they treated him as if he didn't have HIV and that his family was very supportive of him, suggesting that he was not overly concerned whether or not they knew. Paul was appreciative of his family support which made living with HIV easier. Although he was uncertain about the extent of his exposure and about who had exposed him, the extract suggests that when individuals receive effective family support to enable them to cope with HIV, concerns about exposure become less important and relationships with perceived exposers do not become strained. This concept forms the intersection between exposure and disclosure, since disclosure is intended to yield support but can lead to rejection and stigmatization. Similarly, exposure can lead to rejection and stigmatization.

Some of those participants who believed they knew their perceived exposers took the unusual approach of seeking clarification from such individuals. But most of the affected participants would not risk being subject to the consequences of definitive disclosure which would have been necessary if they had sought clarification. As illustrated below, the affected participants' relationships with such perceived exposers became strained thereafter because of the supposed breach of confidentiality.

Interviewer: *And your friend you told and your little brother, how did you make sure they don't tell anybody else?*

Tyron: I suspect that my friend he told someone. Yea, I suspect ... Even when I went there [country of origin], I told my friend. "My dear brother, I think you told Pollycap" [friend's brother]. But of course he denied.

Interviewer. *And how has your relationship with your friend been then since you asked him if he told his brother about your disease?*

Tyron: We are not very close as before. Plus, I live here in England, and he is there in Africa. But I don't share my secrets with him anymore. But he is still my friend. If I go home, he is the only one I can run to in case am in trouble because he knows my condition. And he was there for me when I was completely down. So ya, the friendship is still there, but weaker than before [suspected exposure].

(Tyron, 45 years old, HIV-positive for more than eight years. Has a partner, who lives in country of origin pending the outcome of her UK visa application, HIV-positive, unknown period of time. Tyron's previous partner died of AIDS related illness in country of origin. Has no children)

The above extract illustrates how relationships could become strained if a participant suspected that another person had exposed their HIV-positive status. However, Tyron had sustained his friendship with the individual concerned nevertheless, perhaps assisted by the physical distance between them; and had retained a degree of commitment to someone whom he felt had supported him as he had struggled to come to terms with his condition.

This section has illustrated some of the social contexts in which exposure was seen to take place. The next section discusses the manner in which the information regarding participants' HIV-positive status was communicated to the third parties.

5.3 Uncovering the secret through other people and cues about HIV infection

This section analyses how participants believed that their HIV-positive status had been exposed to others. The data suggest that the information was conveyed in two main ways: through other people who already knew; and/or through cues such as medicines which allowed HIV-positive status to be inferred. Thus, the information can be spread either through cues 'given' or 'given-off' (Goffman, 1959, p. 59). Exposure through cues given involved someone else intentionally revealing the affected participants' HIV status. Exposure through cues given-off involved incidental revelation of the affected participants' condition through detection of indicators such as such as weight loss or the presence of medication.

The affected participants faced a constant risk of exposure through all who knew about their HIV-positive status, including sexual partners and people very close to them.

Peter: Even the partner, you are not sure who the partner will confide in. Maybe the sister [partner's sister]. There are circumstances which are very difficult. So there is always this fear [of exposure].

{Peter, Black African. Works in London for an organisation that provides emotional and social support services for HIV-positive individuals in England}

The service provider quoted above pointed out that once an infected individual had revealed their status to someone, it became impossible to guarantee total confidentiality. The anticipation of possible exposure through other people was therefore a concern to 14 of the participants because they could never be certain about exactly who else knew about their infection, and could not ask others without incurring further exposure. Research participants who partially concealed their HIV-positive status tended to worry that the information could easily reach the people from whom they would otherwise conceal their infection, in particular their family members, as illustrated below.

Rachel: Yea, I worry. That they [Rachel's family in country of origin] know, or may be somebody will tell them [Rachel's family].

[Silence]

Rachel: My cousin is very popular and whenever she passes here we say we are sisters you know ... And if somebody happens to know [that Rachel is HIV-positive], and you know, you [referring to herself] are a sister to so and so, and that one goes pulling one another [meaning gossip]. That is what I always think about. But when it crosses my mind I just dismiss it ... because I wouldn't like, you know, [silence] my family to know about it.

(Rachel, 37 years old, HIV-positive for 8 years. Has a partner, Bill living with her in London, 31 years old, HIV-positive for 7 years. Rachel has an 18 months old son. The child is known to be HIV- negative)

Rachel said she had only disclosed her infection to her cousin because the cousin had been in London at a time when the participant was very ill. As far as Rachel was aware, the rest of her family members, all in her native country, did not know

that she was living with HIV and she preferred that it remained that way. However, she did not have full control over information about her HIV-positive status. Beyond concealing the information from the rest of her family members, there was very little she could do to prevent exposure. Rachel worried that either her family already knew or, if not, then her cousin or someone else might tell them. The concern about their HIV status being revealed accounts for the constant worry with which the participants lived, and their need to carefully select their social contacts. The above extract illustrates the uncertainty surrounding exposure, since this participant could only guess who might expose her, and she had no means of ever dispelling or confirming her worries without disclosing her status. She seems to suggest that her cousin's popularity increased the range of potential exposure. Unable to ascertain who knew about her condition without disclosing her HIV-positive status, Rachel simply 'dismissed' this worry out of her mind.

Fear of exposure through third parties led the 14 participants who partly concealed their HIV-positive status, or the partner's HIV status in case of the HIV-negative man, to try to limit the number of people who knew about their HIV-positive status. According to one service-provider, ongoing concern about exposure through other people could influence participants' choices about which HIV-related support services they accessed.

Anne: We [service providers] get service users who don't want the other person to know that they came to the services. So you [HIV-positive person] might be a friend, and I [another HIV-positive person] know that you go to a certain support group, I will choose to go to a different support group ... And what we do find is that, eeh, say people from Southern Africa. If they kind of like meet here at the support group the first time, the second time you probably won't see them again. They have disbanded because you [HIV-positive individual from the support group] might open your mouth and say something [disclose someone's HIV status], eeh you know, to make other people know [that someone is infected by HIV] back in their country, you know. So you start disclosing about their status. And that, again, it's disclosure [exposure in the terms of the present study]. So that's why may be a person in the east [East London] will may be come to the south [South London], and the one in the north [north London] would go to the west [west London]. Because they don't want to meet.

{Anne, Black African. Works in London for an organisation that provides emotional and social support services for HIV-positive individuals in England}

The service-provider noted that HIV-positive people were willing to travel across London in search of 'safer services' where they were less likely to meet individuals familiar to them or their family members.

Some participants indicated that they had been exposed inadvertently through cues such as sudden weight loss or the presence of HIV-related materials. As illustrated in Table 5.1, five participants believed they had been exposed in this way. Two said they had been exposed by their anti-HIV medication. Another two believed they had been exposed by changes in their physical condition, whereas one believed he was exposed by the changes in his partner's physical condition. Luke, quoted below, had disclosed his HIV-positive status to friends because he believed that they would have suspected anyway on the basis of his poor health and weight loss.

Luke: I was distressed. My health got worse. I lost so much weight. I could not walk easily. I looked terrible. I looked like the way people look when they have AIDS in Africa. So I asked my doctor if I could start treatment. He put me on ARVs. Surprisingly, after just about a month on medication, my immune system responded. I got better. Got my appetite. Felt strong. Started moving about again ... They [friends] noticed I am always unwell. I was not the same like before diagnosis ... So I had to let them know the truth because they were already supportive so much. I didn't want to lose their support, so I decided I tell them so that they know [that he had HIV]. So I said look here, this is what is happening to me. Told each of them separately when I felt it was ok to open up. But I had no idea what to expect. Luckily the three have not run away yet ... You are dealing with medication side effects, fatigue, sometimes you have change in skin colour. It is difficult to hide [HIV-positive status] ... Everyone could see I was not normal.

(Luke, 41 years old, HIV-positive for 11 years. Has separated from partner because of HIV, has no children)

Luke had lost a lot of weight by the time he was diagnosed HIV-positive, a stereotypical sign of HIV in sub-Saharan Africa where medication is not yet universally available. He felt compelled to disclose his HIV-positive status to his close friends partly because he did not want to risk losing their support through attempting to conceal a condition which would have been apparent to them.

The very medications that kept HIV-positive people alive and healthy, more or less eliminating the visible signs of the disease, were themselves potential sources of exposure. Consequently, some participants exercised caution regarding where they kept and took their medication. To reduce the risk of incidental exposure, some of them hid away their medications and HIV-related literature when they were visited by people they were concealing their disease from, as illustrated below.

Interviewer: *You said you have to think of who to invite and you have to plan to invite a friend home. How about when you are the one invited?*

Bill: Yea even, that is another issue. If I have to go [to take medication] I have to hide. Like I hide my medication you understand. I can't take them like when they [other people, friends] are there. I have to go somewhere and take. For instance, I go to the toilet.

(Bill, 31 years old, HIV-positive for 7 years. Has partner, Rachel living with him in London, 37 years old, HIV-positive for 8 years. Bill an 18 months old son. The child is known to be HIV- negative)

The risk of exposure through medication posed a constant challenge because the affected participants had to take their medication at clinician-prescribed times every day for the medications to work effectively. The dual challenge of avoiding exposure, while at the same time adhering to treatment, forced some participants to adapt their lifestyle to suit their confidentiality needs.

In some instances, participants' awareness of their personal circumstances made them suspect exposure that might have never occurred, as illustrated below.

Interviewer: *what are some of the issues that you face as a man living with HIV?*

Luke: There is the issue of stigma. Being HIV is so stigmatized. You always feel someone else knows about you ... I was once exposed when I was trying to do an IT course. This was after my diagnosis. So I was in this IT class. I couldn't concentrate. Was always tired and stressed out. So the lecturer one day told me I don't think you are fit for this class. I don't think you are fit for this course. Something must be wrong with you. I felt like she knew me. It felt like she could see my condition. I felt really bad and ended up abandoning the course. At job again, you always look very tired at meetings. People always asking you why you are the one so tired. What is wrong with you?

You can't tell the truth. Especially, at that time, my boss was just laying people off. I had to pretend and try working harder to keep my job. I didn't want to give him an excuse to sack me

(Luke, 41 years old, HIV-positive for 11 years. Has separated from partner because of HIV, has no children)

To minimise the risk of exposure, Luke tried his best to look and work as normally as possible. He had not disclosed his status but he felt that the people he interacted with could 'see' that he had HIV. He transposed his own awareness of his condition onto the people he was attempting to conceal his HIV-positive status from. Fear of exposure led Luke to quit college. For Luke, at that time, maintaining his confidentiality outweighed the benefits completing his college course. Subsequently, he had not resigned from his job in response to the same fear, but had worked harder to keep his career on track. His words suggest that the desperation to avoid becoming unemployed had overcome his fear of exposure.

Overall, the incidental exposure discussed in this subsection involved inadvertent cues about the participants' HIV status. This was a daily concern for 14 of the 18 participants who managed their surroundings and their circumstances in order to minimise risk of exposure either directly or through inference. The next section discusses the different times in the illness trajectory when exposure of HIV-positive status was seen to have taken place.

5.4 When exposure of HIV-positive status occurred

The aim of this section is to discuss variations in the timing of exposure in relation to identification of HIV. This section is divided into five subsections, the first of which analyses data on exposure prior to clinical diagnosis, when HIV was suspected but its presence had not yet been confirmed. The second subsection analyses cases of exposure which occurred around the time the relevant participants were diagnosed. The third subsection discusses exposure that occurred sometime after the participant had tested positive.

Data is provided to illustrate that the timing of the perceived exposure to persons other than health professionals directly involved in diagnosis and treatment ranged

from before diagnosis, in two cases of suspected HIV, to several months or years after diagnosis. The timing of exposure depended on two major factors. The first factor was the participants' visible health condition. The more discernible were their visible signs of ill health, the higher was the risk of exposure, and, for some at least, the more quickly they were exposed. For example, participants who were acutely ill at the time of their diagnosis were more likely to disclose their status to explain their illness, resulting in an increased risk of third party exposure. These people also displayed discernible HIV associated symptoms, such as severe weight loss and fatigue, further shortening the period between diagnosis and potential exposure. The second determinant was the number of people who knew about the participant's condition. The greater the number of people who knew about their HIV-positive status, the sooner the participant was likely to be exposed.

Reported exposure timing had a similar pattern to the disclosure timing discussed in Chapter 2. But the timings for different participants ultimately depended on their individual circumstances, as illustrated in Table 5.2 below. The table categorises participants into three general groups based on the timing of their perceived first exposure. It is worth noting that those who reported early exposure may have also experienced further unwanted exposure at a later point in their life with HIV. For instance, Robin was exposed before diagnosis and then again later after his diagnosis. Data analyses showed that timing was a key determinant of perceived exposure by the participants. Their efforts towards mitigating the risk of exposure were time-bound, only successful for a period of time, after which they had to revise their strategy or risk exposure because their personal circumstances had changed and they had to provide relevant justifications for the changes. For instance, one participant was diagnosed after experiencing severe weight loss, and had had to conceal its cause. While on medication, she experienced loss of body shape as a result of a medication side-effect called lipodystrophy which making her appear overweight. She also had to avoid certain foods because of the HIV medications. To avoid unwanted exposure of her being HIV-positive, she had to come up with a different justification for her changing circumstances.

Table 5.2: Perceived timing of first exposure (n=18)

Participant	Gender	Age	Exposed	Timing and who they were exposed to
Paul	Male	51	Yes	Point of diagnosis (mother, brothers), later after diagnosis {unspecified timing} (daughter)
Robin	Male	45	Yes	Before diagnosis (brother), later after diagnosis {unspecified time} (mother, rest of family)
Troy	Male	57	Yes	Point of diagnosis (brother), later (partner, children)
Luke	Male	41	Yes	Later after diagnosis (friends, college mates, workmates)
Dan	Male	49	Yes	Point of diagnosis (parents)
Damien	Male	52	Yes	Later after diagnosis (children)
Trevor	Male	47	Yes	Later after diagnosis (partner)
Biden	Male	43	Yes	Later after diagnosis (unspecified)
Phill	Male	51	Yes	Later after diagnosis (children)
Tyron	Male	45	Yes	Later after diagnosis (friends brother)
Lorna	Female	52	Yes	Later after diagnosis (son)
Rachel	Female	37	Yes	Later after diagnosis (cousin)
Millie	Female	54	Yes	Before diagnosis (housemate's friends)
Bill	Male	31	No	Exposure not mentioned during the interview
Robert	Male	40	No	Exposure not mentioned during the interview
Harmony	Female	48	No	Exposure not mentioned during the interview
Melisa	Female	43	No	Exposure not mentioned during the interview
Lucy	Female	35	No	Exposure not mentioned during the interview

Table 5.2 above illustrates that two participants believed that they had first been exposed even before they tested positive for HIV. The perceived exposers noticed what they believed were HIV symptoms, for example shingles in the case of one of the participants, whose housemate passed on the suggestion that she might have acquired HIV to others. Another three believed that they had been exposed shortly after sharing their diagnosis with others, and the majority, eight out of 17 participants, thought that they had been exposed after they had been living with HIV for some time. The data further suggest that there was cumulative risk of exposure for those participants who were living with people from whom they were concealing their condition, as stated by Damien.

Damien: But when you stay with somebody for a long time [unspecified length], time can come and find out. Yea. You can forget your medical information. A letter can come. They can pick a phone while you are out.

(Damien, 54 years old, HIV-positive for 7 years, has 4 children in country of origin from previous marriage. Previous partner died of AIDS related illness in country of origin. Has partner, Lorna who lives independently from him in London, 52 years old, HIV-positive for 11 years, has 2 children. Lorna's 13 year old son who lives in London and Damien's 10 year old son who lives in country of origin are known to be HIV-positive)

The above quote illustrates that the threat of exposure was a ticking clock for some of the participants. Damien suggests, accidents and oversights can happen and perhaps become more likely with the passage of time as vigilance weakens. This dynamic may affect the nexus between disclosure, concealment and exposure. As keeping one's HIV-positive status becomes more difficult over time, individuals may eventually come around to disclosing it to those from whom they had previously kept it hidden, simply to preclude exposure to them. However, this step may, in turn, increase the risk of exposure to others, if those who have been given the information fail to keep it confidential.

Culturally, it was almost guaranteed that any gossip about one's HIV status would become a talking point within the African community. Given that, statistically, Black Africans are the heterosexual group most affected by HIV in the UK, signs such as severe weight loss or being spotted at an HIV clinic were likely to be linked to HIV,

even in the absence of definitive knowledge. Interview material concerning the three different stages of the HIV trajectory identified above is discussed next, beginning with exposure prior to diagnosis.

5.4.1 Exposure of suspected HIV-positive status

This subsection provides analyses of perceived exposure of the suspected presence of HIV prior to diagnosis. Though uncommon, Table 5.2 above illustrates that two of the 18 participants, one male and one female, believed that their likely HIV-positive-status had been exposed before they were clinically diagnosed positive for HIV. One of these participants, Robin, believed he had faced unwanted intentional exposure by inference when his partner revealed her own HIV-positive diagnosis to Robin's brother before revealing it to him. Robin believed that his had inferred from this information that he was likely to also have the condition.

Robin: She [partner] should have told me first. And telling my brother ... that she [partner in the UK] went to hospital, checked herself [took an HIV test], and she found that she is HIV-positive. And by that time ... I have not come back to London [still in country of origin]

Interviewer: You have not tested yourself?

I have not tested, I don't know! So she tells my brother [that she is HIV-positive] ... Well, and do you know the truth? The truth is that all along, I was suspecting that I am HIV-positive. I was meeting friends who had been tested positive. And I was suspecting that I was also positive. But it did not occur to me that I should also test myself.

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

Whether Harmony was merely revealing her own status or trying to get Robin to test for HIV, Robin believed she should have talked to him first, before revealing her status to his brother and by inference, Robin's status too. The example suggests a

concern for loss of control over who knows about HIV in the family. This concern was fuelled by Robin's own suspicion about his health. However, the perceived exposure did not affect Robin and Harmony's relationship over the longer term, and he had informed her that he had suspected he had HIV long before finding out that she had the condition.

The other participant who reported exposure prior to definite diagnosis blamed her housemate for transmitting this information. Just like Robin, Millie had not yet taken an HIV test at the time referred to in the following quotation. But when she developed shingles her housemate made a visual 'diagnosis' of HIV, based on epidemiological stereotypes. Shingles is a common sign of illness among HIV infected individuals in the participants' countries of origin. The appearance of shingles all over Millie's body, which could have been due to a host of other causes, was inferred by her housemate to indicate HIV infection.

Interviewer: *And you just said where you were living [shared flat in London], the woman chased you.*

Millie: *When I had shingles.*

Interviewer: *Was she also from East Africa?*

Millie: *Yes, from my country of origin.*

Interviewer: *And she just saw shingles, did she know the ultimate results?*

Millie: *Me, I didn't know what it meant. I heard her calling other friends telling them, that, "Oh, Millie has herpes, and I know what herpes means [HIV]".*

Interviewer: *OK.*

Millie: *Yes. But she didn't tell me that you have herpes, no.*

Interviewer: *Talking behind your back?*

Millie: *Yes. Complaining to her friends. Then after three weeks, she chased me away.*

(Millie, 54 years old, HIV-positive for 3 years, has 5 adult children in country of origin from previous marriage. Has a partner, Phil who lives independently from her in London, 51 years old, HIV-positive for 9 years. Phil has a wife and 3 children in country of origin. None of the children are known to be HIV-positive)

Millie had been aware of the link between HIV and herpes, but had not known about the connection between the herpes virus and shingles. She felt that her housemate

should have first discussed the perceived HIV-positive status with her before talking to other people. The Millie was convinced that she had been 'chased' from the house because of HIV stigma, not the herpes infection. She ultimately went for an HIV test and had her positive status confirmed. Millie and her housemate shared a socio-cultural background in which HIV is very common, an epidemiological background which led the latter to quickly flag-up symptoms as signs of HIV infection, in this case correctly. Mille had clearly found distressing the experience of her HIV-positive status being exposed before it was confirmed. The next subsection addresses exposure at the time of diagnosis.

5.4.2 Rapid post-diagnosis exposure of HIV-positive status

This subsection analyses perceived exposure that occurred shortly after participants tested positive for HIV. Three of the 17 participants believed they their HIV-positive status was exposed beyond the healthcare system at the time of their diagnoses. This rapid exposure occurred because they were critically ill and hospitalised when they took an HIV test.

Interviewer: *And who told your parents about your status?*

Dan: Hmm, unfortunately it was my sisters! Because, when they came, and when then they took me for testing, and then they left me at the hospital [Hospital in country of origin]. They went to the village, and then they told my parents that they had left me in a very bad condition. And when they [the parents] asked them [the sisters] I think for them they thought twice. They [sisters] thought that they had to tell them [parents]. By then there was HIV death every day. But looking back I think they didn't do the right thing because they did it without my consent ... Even if they didn't [expose] one day I would have told them [parents]. Or they would have suspected. Or they knew coz I was about to die. By the time I tested ... I had lost so much weight. By then I was 76 kilograms, but by the time I was tested I was 50Kgs. So you can imagine loosing 26 kilos is not a joke. So even if I didn't tell them, you didn't have to tell anyone, but then just the look of you [sarcastic sigh].

(Dan, 49 years old, HIV-positive for 12 years. Has 2 children in country of origin from previous marriage. Has partner, who lives with him in London, not interviewed. Dan has 3 children in London, one of them a step-daughter from

the partner's previous marriage. Dan's 12 year old daughter in country of origin is known to be HIV-positive)

Dan tested for HIV whilst still in his country of origin, before migrating to the UK. Although he reported some uncertainty about the thinking of his sisters who had exposed his diagnosis to his parents shortly after it was confirmed, he was fairly sure that they had done so because they had felt that his condition could not be concealed from the former for long. Nevertheless, looking back at this process, Dan would have preferred it if his sisters had not revealed his HIV-positive status to his parents, giving him time to tell them. This example illustrates the connection between disclosure, concealment and exposure. By disclosing his condition to his parents, his sisters had precluded him from choosing when to tell them himself, although they might have found out anyway due to the visibility of his condition. However, over a longer time period, he had become more accepting about what had happened.

Interviewer: *And have you ever talked about it [his sisters telling his parents that he was HIV-positive?*

Dan: *I think better by-gone things be by-gones ... After all they saved my life, so? Even if they didn't [expose] one day I would have told them. Or they ... they [parents] knew [before sisters told them].*

(Dan, 49 years old, HIV-positive for 12 years. Has 2 children in country of origin from previous marriage. Has partner, who lives with him in London, not interviewed. Dan has 3 children in London, one of them a step-daughter from the partner's previous marriage. Dan's 12 year old daughter in country of origin is known to be HIV-positive)

The next subsection discusses perceived exposure sometime after diagnosis.

5.4.3 Slower exposure of HIV-positive status

Eight of the 13 HIV positive respondents who were concerned about exposure indicated that their HIV-positive status had been exposed to at least some others a considerable time, between a few months to several years, after their initial diagnosis. The data suggest that the participants who successfully concealed their

status for a longer period of time were mainly those who lived far from the people they wanted to hide their status from. This was partly why some of the participants reportedly avoided support services where they might meet people known to their family in their country of origin, as discussed in Chapter 4.

Some participants concluded that they had been exposed when they detected or suspected that certain individuals who they had not told about their status, knew of their infection, as illustrated below. At the point of exposure, most of the participants who were exposed long after diagnosis did not have visible signs of infection, but could still be exposed through HIV-related cues such as the presence of medications in one's house, which they tried to manage. The following quotation refers to the other major source of exposure, namely the breaking of confidence by second parties whom the participant had told about their condition.

Interviewer: *But you didn't tell anyone at work?*

Tyron: *No! I didn't tell. If I tell it would be very difficult for me. They would gossip in the whole area.*

Interviewer: *And your friend you told and your little brother, how did you make sure they don't tell anybody else?*

Tyron: *Of course that's the thing. I don't know. I think, now, I suspect that my friend he told someone. Yea, I suspect.*

Interviewer: *Why do you suspect?*

Tyron: *Because I have got a brother here [England]. They are closer [with the friend's brother]. Because he came here [England], this friend's brother. He used to talk, talk to me. And his [the friend's] young brother here, he went there back home. And I saw him when he came back [to England], not like before anyway. He used to talk to me, not now. When I call him, "Oh am busy am busy".*

Interviewer: *So you suspect?*

Tyron: *Yes. Even when I went there [country of origin], I told my friend. My dear brother, I think you told Pollycap [friend's brother]. I explained to him [the friend] that I think he [friend's brother] does not speak to me like before.*

Interviewer: *Were you worried about them telling somebody all the time?*

[Deep sigh]. Yea, sometimes worried sometimes saying, "Oh God, what can I do?" Yea.

(Tyron, 45 years old, HIV-positive for more than eight years. Has a partner, who lives in country of origin pending the outcome of her UK visa application,

HIV-positive, unknown period of time. Tyrone's previous partner died of AIDS related illness in country of origin. Has no children)

The above example represents some common features of the experiences of participants whose HIV-positive status was exposed after a period of time living with HIV. The example highlights the loss of control that ensues when disclosure of HIV-positive status creates the risk of exposure to third parties, which can escalate exponentially as information is passed on. Uncertainty about whether exposure has occurred, and if so, to what extent, can make this loss of control particularly stressful for individuals who, like Tyrone, are trying to limit knowledge about their condition. Although he confronted his friend about his exposure when they ultimately met, he could only take his word for it that he hadn't told anyone, and could not confirm or disconfirm his suspicion.

The following subsection offers an analysis of meaning the affected respondents attributed to the perceived exposure.

5.5 Making meaning of the perceived exposure

This section analyses the types of exposure the affected participants believed they experienced. From data analyses, the various forms of exposure the participants reported could be categorised differently depending on what the participants believed had happened to the information regarding their HIV status. As discussed above, there was no way the concerned participants could confirm whether or not their HIV status had been exposed by and to those they suspected without risking their confidentiality. Many were therefore uncertain about whether the perceived exposure occurred or not, how and why. However, the discussions below demonstrate that in some cases, the relevant participants believed they knew who exposed them or when they were exposed. For the sake of the present analyses, the reported cases of exposure can also be categorised on the basis of the perceived intentions of those suspected of exposing the participant's HIV status.

This section is divided into two subsections. The first subsection presents data analysis on the participant's certainty regarding their perceived exposure. The data

presented below illustrates the direct and indirect evidence used by some of the participants to explicate their perceived exposure. The second subsection discusses exposure categorises based on the concerned participants' perceived motives of their human exposers. Interview extracts are used to illustrate that the participants assessed the motives of the perceived exposers and judged their intentions as malevolent or benevolent. The next subsection analyses the degrees of certainty or uncertainty about the perceived exposure.

5.5.1 Uncertainty about exposure of HIV-positive status

In this subsection, the issue of certainty versus uncertainty about the exposure of HIV-positive status will be considered. In some cases, participants believed that they knew beyond doubt that they had been exposed, who had exposed them, and to whom they had been exposed. In other instances, the concerned participant felt uncertain about one or more of these features of exposure. As pointed out already, the concerned participants could not easily verify whether others knew about their status without revealing that they were HIV-positive. However, based on the small number of people they had confided in, some participants felt they could be certain about which of these had revealed their HIV-positive status, as illustrated below.

Interviewer: *And apart from your partner and your partner, who else knows you are living with HIV?*

Phil: *My first-born*

Interviewer: *Who told him?*

Phil: *My wife*

Interviewer: *Ok*

Phil: *She [the partner] told him that, "You boy, you have to be very careful. This is the condition [meaning HIV]. This condition is bad. That's how your dad is living with this condition. So you have to take care."*

Interviewer: *Why did she decide to tell him and not her?*

Phil: *I think she told even the girl but she did not want to tell me [that she had told them].*

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of

origin from previous marriage. None of the children are known to be HIV-positive)

Phil was certain that his partner had told his son about the father's HIV-positive status, using his condition as a negative exemplar demonstrating the need to be careful to avoid infection. But he felt uncertain about whether she had also told his daughter. But like the rest of the participants who believed their HIV status had been exposed, Phil could not check with his daughter as whether she knew he had HIV without revealing or at least hinting at his condition, and therefore could not confirm or disconfirm his suspicions about the perceived exposure.

Given that chains of communication might expand out of control, participants could not tell how far knowledge about their HIV-positive status might have spread, as suggested in the next quotation.

Interviewer: *Who told her?* [Robin's sister]

Robin: *Because she [sister] knew already because now, everybody, my family they now knew, the brother knew, she [sister] knew, my mother knew. I don't know whether there are other people they knew but I don't know ... I don't know at what point they knew [family members].*

Interviewer: *How do you confirm when they [family members] know, or how do you suspect that so and so knew?*

Robin: *I knew that she [sister] knows because when she came in, she came to live with me ... And this parrot here, this my wife here, she can't stop without telling people that, eeh, that there is HIV disease and things like that.*

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

The above extract suggests Robin believed that his sister already knew about his condition, and that the source of this information had been his partner. But Robin felt uncertain about who else in the family was aware of his condition, and about when any such people might have learnt about his disease. However, Robin could

not directly ask other members of his family whether they knew about his infection without further risking his confidentiality.

Given the widespread uncertainty about perceived exposure discussed above, the concerned participants relied on deduction from clues to judge who might know about their HIV-positive status. The main suspects who were blamed for exposure were the individuals who knew of the affected participant's positive status.

Interviewer: *At the moment, who else knows that you have HIV apart from the support services?*

Biden: *I have never told anybody, but you know rumours in African societies can move like wind you know? I do not know, they don't tell you, but they know. Because of her [the partner] behaviours, you know ...*

Interviewer: *And here [referring to England], you have never told anybody?*

Biden: *Some people know. Sure, I don't give a damn, if they know or they don't know. What difference does it make? Hmm?*

Interviewer: *Ok. How do you think they [those perceived to know his status] came to know?*

Biden: *Through her [referring to the partner] ... because she has been moving with wrong characters, you know.*

Interviewer: *Ok. Is there anything you have observed that makes you think that may be they know about your condition?*

Biden: *Yes, behaviours.*

(Biden, 43 years old, HIV-positive for 11 years, has no children. Separated from partner Melisa, 43 years old, HIV-positive for 13 years, has 1 adult child. Biden and Melisa still visit each other. Melisa's 13 year old son is known to have died of AIDS related illness in the UK)

The above quote illustrates that the participant believed that his partner had disclosed his status. As with Robin, who referred to his partner as a 'parrot', the common view among the men that their partner had exposed their HIV-positive status reflected male gender stereotypes about women's propensity to gossip. Biden saw a propensity to spread rumours like 'wind' as an attribute of African culture. Consequently, regardless of how effectively the affected participants tried to conceal their status, others were eventually bound to find out about it. In the absence of direct communication, Biden had looked for behavioural evidence concerning who knew about his HIV-positive status. For example, Biden believed

that he could tell from the actions of his partner's friends that they knew he was HIV-positive. The drawback with this approach to identifying exposure is that it must be difficult to avoid reinterpreting others' behaviour to fit suspicion. Perhaps aware of these doubts, Biden expressed indifference about the extent to which his condition had been exposed to others.

The researcher was able to compare exposure accounts in the three cases where both partners were interviewed. These comparisons show that some of the exposure accounts did not match up. For instance, Biden's quote conveys his certainty that his partner had exposed his status to her friends. However, the partner, Melisa, declared that she had never discussed even her own status with anyone else, including her friends, as illustrated below.

Interviewer: *Here in the UK, who knows you are living with HIV?*

Melisa: My doctor, the HIV specialist and the nurses over there [HIV clinic]. They are the only ones who know, and my partner.

Interviewer: *How about your friends?*

Melisa: No, they don't know.

Interviewer: *Ok, is that something you decided they are not going to know?*

Melisa: Yes!

Interviewer: *Any reason if I may ask?*

Melisa: Yea, people from my country, once they know you have got HIV, you will be the story. When they are like in a place for drinking, the entire story they will bring about is about you ... So that's why I don't tell anybody. I just keep it by myself and my partner.

(Melisa, 43 years old, HIV-positive for 13 years, has adult daughter. Separated from partner, Biden, 43 years old, HIV-positive for 11 years, has no child. Biden and Melisa still visit each other. Melisa's 13 year old son is known to have died of AIDS related illness in the UK)

Unaware that Biden believed she had exposed him, Melisa gave an account which contradicts Biden's assertion that she had discussed HIV with her friends. Indeed, Melisa stated that she was so concerned about exposure by other people that she had never joined an HIV support group in the 13 years during which she had lived with the disease in the UK. The contrast between Melisa and Biden's accounts of exposure suggests that some of the participants were worried about exposure that

possibly never occurred. Such concerns arose from the expectation that other people, particularly those from African cultures, were bound to gossip, combined with living in an informational trap in which others knowledge could not be asked about directly without creating a new risk of exposure.

The next subsection considers variations in the perceived intentions of those who were assumed to have exposed participants' HIV-positive status.

5.5.2 Perceptions of intentions underlying exposure of HIV-positive status

This sub-section focuses on participants' interpretations of the intentions of people who had exposed their HIV-positive status. Overall, 14 participants, including 12 of those who were HIV-positive, identified instances of deliberate exposure undertaken for dubious or malicious reasons, such as harming relationships, tarnishing their reputations, or to stigmatize them.

Regardless of its motivation, participants were worried about the risks they faced as a result of the perceived exposure, mainly that stigmatization associated with HIV which would add to their existing stigmatized attributes such as unemployment, ethnicity and immigration status. Moreover, the affected participants had no control over the actions other people with knowledge about their positive diagnosis, as discussed above. Consequently, they worried that individuals with such knowledge might reveal their HIV-positive status to those from whom they most wished to conceal it. This was one of the main reasons why communication about HIV status remained such a guarded affair for most participants. However, the following account demonstrates that accounts of the reasons for exposure could vary substantially.

Robin: One day I was writing a letter like this to the lady back home [partner in country of origin]. And I got drunk, and I left the letter unfinished on the table. She [Harmony, partner in the UK] took the letter and wrote down there [meaning at the bottom of the letter] ..., "Do you know that your husband here is HIV-positive?" And she posted the letter to her [partner in Africa] without my knowledge! The lady [partner in Africa] just wrote back to me ... posted

me back the letter. I opened it like this, "Aahh" [demonstrating disbelief]. This is very funny story. I said, "Why did you [partner in the UK] have to tell her [Partner in Africa]?" "So why do you [Robin] want to infect her? [Partner in Africa]" [Partner in the UK asked]. In other words, she [partner in the UK] just doesn't want me to marry and continue with our relationship [with partner in Africa]. But at the same time, because it is not her [partner in the UK] problem, it's not her business anyway. So anyway that is how the story went.

(Robin, 45 years old, HIV-positive for 13 years. Has partner, Harmony living with him in London, 48 years old, HIV-positive for 14 years. Robin has 2 biological children and 4 adopted children from Harmony's late sister who was known to have died of AIDS related illness, 3 of the children are adults who live independently in London. None of the children are known to be HIV-positive)

Robin had constructed an account of Harmony's interpretation of her reason for exposing his HIV-positive status to his former partner living in Africa, namely to prevent him from infecting the latter. However, he rejected this concern as illegitimate, 'not her business' despite its public health rationale and felt that his UK partner's true motive was to bring about an end to his relationship with the other woman in Africa.

Participants perceived generalised stigmatization and discrimination to be common in their culture, a concern which exacerbated their anxiety about exposure of their HIV-positive status. Some participants were concerned about a cultural tendency among Black Africans to gossip, as illustrated below.

Interviewer: *And apart from your wife and the boy, who else in your family knows about your status*

Phil: *Nobody?*

Interviewer: *Why is that so?*

Phil: *Eeeh, I didn't want to disclose my status to the whole family. Because of stigma. Especially back home the stigma is huge, it is still there. If you tell this one, you will end up telling the whole village*

(Phil, 51 years old, HIV-positive for 9 years, has wife and 3 children in country of origin. Has girlfriend, Millie who lives independently from him in London, 54 years old, HIV-positive for 3 years. Millie has 5 adult children in country of origin from previous marriage. None of the children are known to be HIV-positive).

The above quotation shows how concern about the tendency to gossip, viewed as a feature of African culture, and stigmatization could come together to make exposure of HIV-positive status particularly harmful.

5.6 Summary

This chapter has shown that exposure - communication about an individual's HIV-positive status without their consent - was of great concern to those affected. The data explored concerns expressed by HIV-positive individuals about the risk of exposure by those to whom they had revealed, or who knew about, their condition. Those in a position to expose a participant's HIV-positive status included family members, friends and workmates who they had either confided in, or who had detected clues indicating the likely presence of HIV.

Two important dimensions of exposure perceptions were explored: firstly, the extent to which the respondent felt certain or uncertain as to whether exposure to particular individuals or more generally had occurred; and, secondly, the extent to which the exposers' motives were seen as benevolent as against malicious. Lastly, the chapter illustrated that HIV status exposure was a lifelong risk for these participants.

The next chapter will discuss these findings in relation to the existing body of research on communication about HIV-positive status, with particular reference to immigrant Black Africans living with their families, the UK heterosexual population most affected by the disease.

CHAPTER SIX

DISCUSSION AND

CONCLUSIONS

CHAPTER SIX. DISCUSSION AND CONCLUSIONS

6.1 Introduction

The aim of this chapter is to critically reflect on the present research process and the findings, which were discussed in detail in the previous three chapters. The chapter is divided into eight sections, beginning with this introduction. The second section provides an overview of the study. The third and longest section critically analyses the present study findings in relation to the existing body of knowledge. It discusses how the theory of communication about HIV status generated from the present study adds to the existing knowledge on communication about HIV status within the affected families of the study population. It also discusses the relevance of the theory of communication about HIV status to the broader communication about other sensitive issues such as mental illness. This section illuminates the psychosocial considerations individuals make regarding communication about their stigmatized conditions. In the present study, there were both private and public health issues that influenced communication about HIV-positive status, as highlighted in the methodology chapter. The fourth section discusses the strengths and limitations of the study. The fifth section reflects on the challenges encountered throughout the research project. The implications of the present study to policy and practice are then outlined in the sixth section, and the penultimate section provides recommendations for future research. The final section provides a summary of the key issues.

6.2 Study overview

The aim of this study was to explore the perspectives of Black East-African men and their families on what it means to live with diagnosed HIV and how services can most effectively respond to their needs. Initial data analyses showed that communication about HIV-positive status was one of the major concerns for the

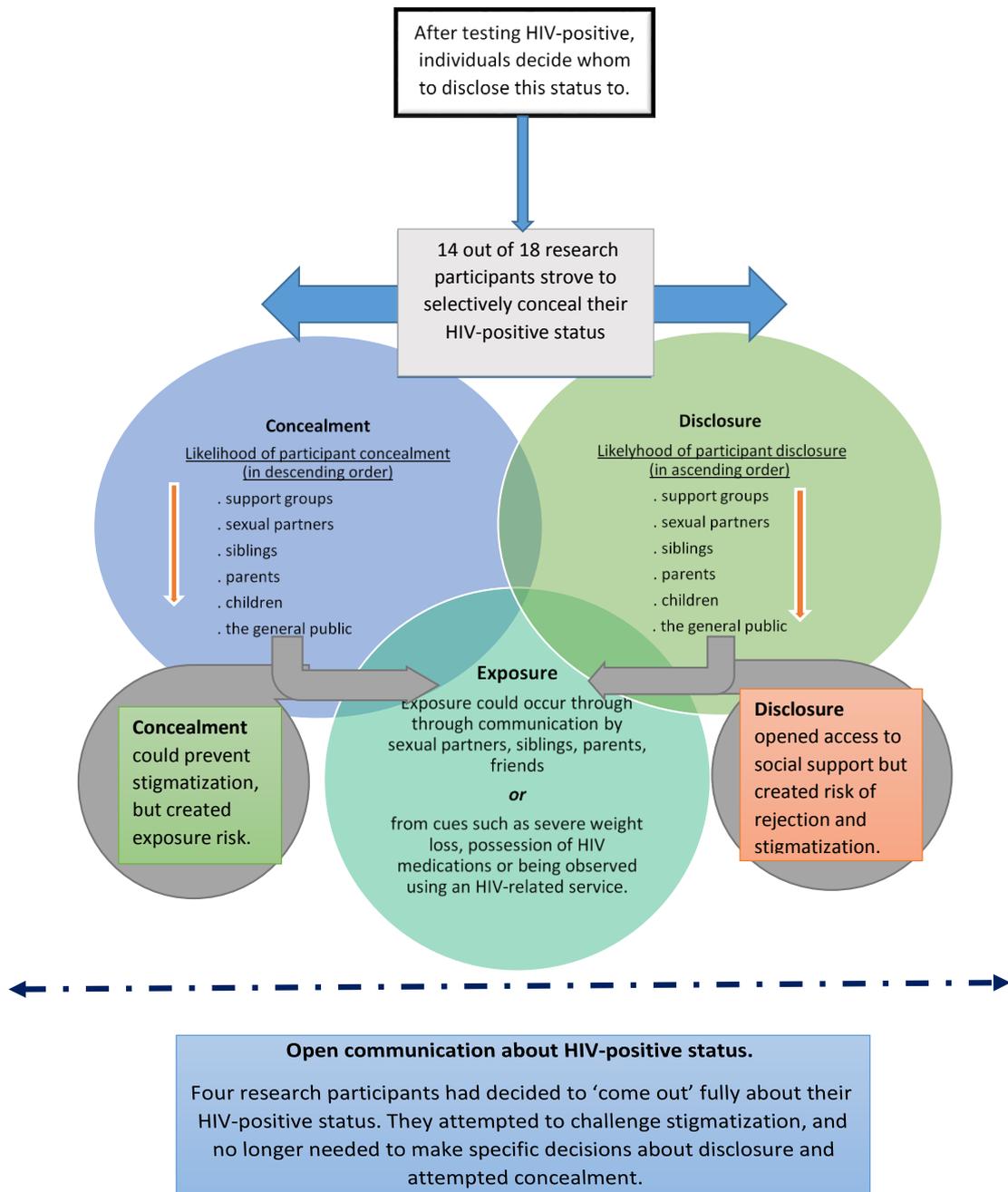
study population. Consequently, the focus shifted to explore how these respondents managed communication about HIV-positive status within and outside their families. Understanding the perspectives of this study population highlights the impact of intra and intercultural interactions, as well as their marginal socioeconomic status in the UK, on their family life with HIV in a society that had become less tolerant of immigrants. There is a scarcity of research focusing specifically on this study population, where there is both a high prevalence of HIV and persistent late diagnosis, making the findings particularly relevant to public health. The men and their families were additionally prone to mental health problems stemming from their lower socioeconomic status and ethnicity. These combined vulnerabilities affect both access to and use of public health initiatives. Collectively, the participants' ill health affected the public health in the UK and in their native countries. The theoretical research interest stems from enquiry into how interactions of different cultural contexts affect communication about stigmatized conditions among transnationals.

Overall, 23 in-depth interviews were conducted. The sample included 11 HIV-positive men, five HIV-positive women and five workers from community organisations. Additionally, the researcher sought sero-discordant couples in which only the man was living with diagnosed HIV, in order to explore whether their perspectives on family life contributed to the emergent theory on communication about HIV status. However, the researcher was unable to recruit such couples due to challenges in accessing potential participants, as discussed in the methodology chapter. The researcher managed to recruit and interview a sero-discordant couple in which the man was HIV-negative and the woman was HIV-positive. The data from the sero-discordant couple, although insufficient to draw conclusions from, were similar to the concerns of sero-concordant couples regarding communication about HIV status. The researcher also made subsequent contact with some participants, in order to fill information gaps identified during the data analyses and to check if there had been any shifts in their views on family life with HIV. Additionally, the researcher used member checks to validate his interpretations of the respondents' perspectives. The participants who were contacted for member checks generally

agreed that the findings reflected their perspectives regarding communication about their HIV-positive status.

The findings showed that one of the men's, and their partners', primary worries was managing who knew about their positive HIV status. The model below, also used in the Introduction to the thesis, is reused here to summarise how the participants managed communication about their HIV-positive status.

Figure 6.1. A Model of Research Participants' Decision-Making about Disclosure of Their HIV-Positive Status.



Whereas disclosure of HIV status was crucial in unlocking access to social support and HIV-related services, it also created the risk of rejection and stigmatization by the recipients. They could opt to conceal their status to avoid the adverse outcomes

that accompany disclosure, such as the risk of being rejected and stigmatized; although in doing so, they forfeited access to the potential support they would otherwise garner by revealing their status. These participants could not predict the response they would get from disclosure without risking their confidentiality. Furthermore, HIV status disclosure does not guarantee access to social support, whereas concealment increases the risk of exposure to the very people the HIV-positive status was hidden from. Thus, whether the relevant participants disclosed or concealed their sero-status, they faced a constant risk of exposure, as discussed in Chapter 5. However, four participants provided an alternative response to the challenge on communication about HIV status. This was especially true for male respondents who are known to be reticent about their HIV status or other health concerns, as documented in previous literature. Open communication about HIV status potentially provided an alternative that most men from the present study population were unlikely to accept due to their reticence to disclose their HIV status.

Unlike previous studies that use the term 'non-disclosure' to refer to a decision to not discuss one's HIV-positive status; concealment is used in this thesis to emphasise a deliberate strategy to ensure that specific recipients would not discover one's HIV status, for as long as desired by the HIV-positive person. The respondents' concealment efforts were aided by a lack of any visible signs of the disease that might signal to casual contacts an underlying infection. The participants were thus mostly concerned about the close social contacts whose familiarity with the participants meant they were more likely to recognise clues to the disease.

Unlike disclosure or concealment of HIV status that involved conscious decisions by the relevant respondents, the findings showed that the participants did not have control over when or how exposure of their status occurred. This loss of control over the information about their positive sero-status was a major source of concern for the affected participants because once someone else learnt of the information, it could never be unlearned, creating further risk of exposure. Those who knew about the diagnosis gained control over the information and were able to decide when and with whom to share it, unknown to the relevant participants. But the information about one's HIV status could also be passed on through non-human cues such as discovery of anti-HIV medications. Thus, exposure occurred through information

'given' or 'given off' (Goffman, 1963). Information 'given', the main concern for the affected participants, involved someone else intentionally telling a third party about the infected individual's HIV status. Information 'given off' involved signs of the underlying HIV infection through one's actions, behaviour or physical changes such as severe weight loss. One participant said that relatives in his native country were convinced he had HIV, only for them to change their view when they saw him 'healthy' again after successful therapy in the UK. This highlights how respondents' social networks used physical appearance to judge whether or not an individual had HIV, based on whether they appeared stereotypically infected or healthy. To minimise the risk of such exposure, the apprehensive participants carefully selected their social contacts and services in order to minimise potential exposers. They also judiciously managed their home environment to eliminate any clues to their disease, such as their HIV medications.

As discussed further below, the present study adds to the existing body of knowledge on communication about HIV status. For instance the findings show that Black Africans in the UK selectively disclosed and concealed their HIV status from significant others, supporting what was previously reported by Calin et al. (2007). However, the present findings introduce the concept of HIV status exposure to emphasise the risk concerns of those infected, unlike some previous studies which used the terms secondary or unintended disclosure to refer to revelation of one's HIV status by a second party. Overall, the study illustrates that disclosure, concealment and exposure are communication strategies used by an HIV-positive individual to manage the flow of information about their condition and their daily life with diagnosed HIV. Unlike some previous studies which looked at disclosure and non-disclosure as one-off independent occurrences, this study illustrates that concealment is a more focused, carefully managed, ongoing process; and that disclosure and concealment are interdependent options continuously and variably used by HIV-positive individuals in different social contexts. This is especially true for transnationals, whose social contacts simultaneously occupy two different cultural contexts. The following section reviews the present findings in relation to the existing body of knowledge.

6.3 Review of the main findings in relation to previous research

The aim of this section is to critically review the key findings outlined above in relation to extant literature. The discussion is organised around the three strategies of communication about HIV-positive status, as examined in the findings; namely disclosure, concealment and exposure of HIV status. The section is divided into four subsections. The first three are dedicated to disclosure, concealment and exposure. The last subsection reviews the relevance of the theory of communication about HIV status, developed from the present study, to other stigmatized conditions, as well as the study's potential implications for formal theory development.

6.3.1 Disclosure of HIV status

There has been considerable research into disclosure of HIV status, as the literature review in Chapter 1 demonstrates. A review of previous research into disclosure of HIV status by Obermeyer et al. (2011) shows that disclosure of HIV-positive status to family members and other social contacts is a major issue for those living with the condition across settings and population groups. Even in developed countries like the UK, disclosure of their positive status is a major concern for most of those living with HIV, who largely belong to marginalized populations such as MSM, immigrants and injecting drug users. A study undertaken in San-Francisco (Skinta et al., 2013) demonstrated that, even in a city seen as highly tolerant and containing a large, active community of people living with HIV, gay men reported similar concerns to those mentioned by the heterosexual participants in the present study. They were worried about the risks of rejection, isolation and loneliness, leading to widespread concealment of HIV-positive status from family members, particular parents. Similarly, HIV-positive injecting drug users have also been reported to struggle with disclosure of their status because of multiple, layered stigmatization (Rudolph et al., 2012). However, there is evidence that individuals are more likely to find disclosure of their HIV-positive status challenging if they face layered stigmatization. For

instance, a study carried out in the USA (Overstreet et al., 2013) found that HIV-positive Black MSM are less likely than White MSM to communicate openly about their HIV status, perhaps because it adds to a cumulative burden of stigmatization which heightens fear of rejection.

The present study was not comparative, but it can be speculated that common reticence about disclosing HIV-positive status among the research population was fuelled by other forms of stigmatization associated with being a Black African and an immigrant. The findings document the dynamics of disclosure from the perspectives of a group who have been little studied but who are the heterosexuals most affected by HIV in the UK (HPA, 2012b). Most previous studies into HIV status disclosure have focused on settled populations. Little is known about the perspectives of heterosexual White British men and their families on communication about HIV-positive status. Such data would allow comparisons to be made in relation to a condition now largely seen as an 'outsider' disease which mostly affects marginalized populations (Kingham, 1998).

The present findings show that HIV status disclosure as a process was gradual; and that attitudes towards disclosure of one's HIV status change with time. As Amoran (2012) reiterated, HIV-positive individuals delay disclosure of their condition for various reasons. It could be because they require medical and social support as the disease progresses or because the infection becomes harder to conceal when the illness progresses to an AIDS-defining state. For instance, one participant said that he suspected that he had HIV long before he went for a confirmatory clinical test; but never shared his suspicions with family members. Such individuals sought medical care for what they believed were HIV-related illnesses, initially concealing their suspicions from the clinicians. Some ultimately revealed their concerns and requested to be referred for an HIV test when they believed the clinicians failed to detect the underlying infection, which the clinical tests ultimately confirmed to be HIV.

The findings show that HIV status disclosure responses by HIV-positive individuals divides into three broad categories: those who were happy to reveal their HIV status to their social contacts; those who revealed their disease only selectively; and those who revealed their status only to health care professionals to access care, whilst

simultaneously concealing it from as many of their social contacts as they possibly could. This finding is consistent with that of Mayfield et al (2008) who suggested that HIV-positive individuals can generally be grouped into open disclosure to everyone, selective disclosure to some people and concealment from most or all social contacts. However, consistent with Obermeyer et al. (2011) the present findings reveal that selective disclosure to a growing number of people was more common than full disclosure to all, while disclosure to none was uncommon. As outlined above, four of the 18 participants had transitioned from selective disclosure to some, to full disclosure to all. The findings also highlight that disclosure decisions are dependent on varying considerations. Selective disclosure was chosen mainly to access health and social care as well as social support. Open disclosure was largely aimed at de-stigmatizing the disease among HIV-positive individuals' social contacts and the wider society. Thus, selective disclosure was guided by personal risk considerations, whereas open disclosure was for wider public benefit. Individuals who had transitioned to public disclosure were those who had overcome their initial fear of the consequences of exposure and who were happy to share their experiences in order to challenge HIV stigma.

The data suggest that concern for criminalization and a perceived duty of care prompted disclosure to sexual partners. This is consistent with previous findings by Stutterheim (2011, 2012) who reported comparable disclosure patterns among Black Africans in the Netherlands. Some of the respondents revealed their status to their sexual partners immediately following a positive test result in order to initiate testing and access to treatment for their partners. However, there were cases involving some partners for whom disclosure did not necessarily lead to access to care, due to the inadequate availability of healthcare in some countries. One participant said his partner died of AIDS because of lack of treatment in his country of origin at the time, despite his prompt action to alert her to his own positive diagnosis. Since the man was in England at the time, where he had access to free healthcare, such disclosure raises ethical questions worthy of future research. Given that HIV stigma in sub-Saharan Africa is widespread, yet access to relevant services is limited (Linda, 2013; Madiba, 2013; Musheke et al., 2013), the rationale for telling the woman, who potentially worried to her death, requires greater scrutiny because

HIV-positive diagnosis remains a death sentence for people without access to treatment (Larkan, 2004). The promotion of disclosure in richer nations such as the UK is underpinned by freely available HIV treatment to all who need it. But some disclosure recipients of the present study population were based in settings where treatment was either not freely available or was inaccessible to potential service users. Thus health promoters need to consider the implications of disclosure by HIV-positive members of the present study population to their social contacts in settings with inadequate healthcare. One such implication highlighted in this study is the request for medications by the participants' relatives in their countries of origin. However, as Shacham (2012) noted, the present findings illuminate the overall importance of HIV status disclosure for enhanced individual social support and at a societal level by reducing transmission risk behaviours and stigma.

A further significant finding reported for immigrant Black Africans residing in rich nations such as Sweden (Asander et al., 2009), was the low levels of disclosure to children. The findings also highlighted some of the challenges faced by parents or guardians regarding disclosure of HIV status to children; and the parents' responses to such challenges. The present findings underlined a mismatch between parental desire to tell children about HIV in the family and the feeling that they lacked the necessary skills to do so, as previously reported (Madiba, 2013). Three female participants in the present study reported that their children were told about HIV in the family by support service staff because they felt unable to do so themselves. Disclosure of HIV status to children is likely to be psychologically and socially challenging (Rochat et al., 2013), prompting some parents to seek help from HIV support services, using what Loubiere et al. (2009) called intermediary disclosure. This finding stressed the invaluable role of HIV support staff in assisting parents from the present study population to overcome their inability to disclose HIV in the family to children.

The present findings highlight the contrasting perspectives of transnational parents, who belong to a stigmatized minority population in the UK, with their children, who may be growing up in a different cultural context to their parents. The children represented in the present study were used to an environment where open dialogue is the norm, in contrast to their parents' experiences of communication being

determined solely by the parents. For this reason, the affected parents sometimes struggled to reveal their own or their children's HIV status. Such disclosure was further influenced by the age, as some parents believed their children were too young to be told about HIV in the family. As discussed in Chapter 3, the chapter on disclosure, the older children were more likely to be told about HIV in the family. But the narratives illustrated great uncertainty about 'how old' was old enough. Some scholars (Krauss et al., 2013) have tried to delineate the optimum age for disclosure to children by suggesting full disclosure is appropriate for those aged six to 12 years, and partial disclosure is appropriate for children under six. The present findings suggested that affected parents preferred disclosure to children in their teens. Four of the present participants had 13-year-old children who, in the concerned participants' views, were still too young to be told about HIV in the family.

Culturally, disclosure to children of HIV in the family was associated with discussing parental sexuality. This somewhat taboo subject is discussed further below. As Heeren et al. (2011) also observed, the challenge was greater when such disclosure involved a perinatally infected child since the parent, often the mother, had to explain how the child had become infected. These parents feared that disclosure of a child's HIV status would increase the risk of exposure, and consequent HIV stigma, towards the child and possibly the entire family. Revelation of HIV in the family to children was therefore an individualised process that depended on each family's circumstances. For instance, participants who had become very ill disclosed their HIV status to their older children. As Gaskins et al. (2011) reported, such disclosure to children became necessary when parental health needs increased. As one parent explained, their illness had triggered risk thinking that led to them revealing the underlying HIV infection and the possibility of their death.

Another finding was that parental assumptions, particularly in men, regarding the children's extant understanding of HIV, created the very risk of exposure that some of the affected families wished to avoid. These parents seemed to assume an objective ignorance among their children about HIV, underestimating the influence of the media, their friends, and the education system on the children's subjective knowledge and understanding of HIV. Two male participants emphasised their children's inability to comprehend what it meant to be HIV-positive, although the

partner of one of the men narrated how the children were actually more knowledgeable about the disease than some of the parents realised. The participant noted that these children were very inquisitive about the parents' source of infection, prognosis, and other infected family members. One female participant believed that the children from the study population, growing up in the UK with readily available information about HIV, made them more knowledgeable and inquisitive relative to their peers in the participants' countries of origin, where there may be a dearth of information and the cultural norm is not to question parents. Consistent with research by Madiba, (2013), the findings indicated that disclosure to children was framed as a risk reduction strategy that required careful timing in order to protect children from potential harm or stress, and the family from subsequent exposure, particularly as the children could not be expected to maintain confidentiality and the resultant risks might be isolation and stigmatization. Some parents also saw disclosure as an opportunity to caution children about managing their own future risks. Consequently, the narratives of the affected parents implied that the best time for disclosure to children was around puberty, just prior to the time when they were more likely to expose themselves to behaviours that heightened the risk of acquiring HIV.

A key finding was the role played by women in disclosure of HIV in the family. None of the male participants had revealed their illness to their children. Some of the men falsely believed their children knew about their condition through their partners, but some of the women said that they also found it very challenging to disclose even their own status to their children. As discussed above, some of the women used HIV support services to reveal their own and their infected children's HIV status to children. This apparent contradictory account regarding disclosure to children is further supported by the men's claims that their partners exposed their HIV status, suggesting a gender-based expectation of the men for the women. Thus, the women shouldered the burden of disclosure for the entire family in managing the revelation of not only their own HIV status, but also those of their partners and HIV-positive children, to both family members and often, the children themselves. Given their cultural background and the documented nurturing role of women in the African context (Loubiere et al., 2009), the present findings suggest that women controlled

the flow of communication about HIV in the family despite their concerns and anxieties about their own confidentiality and risk of exposure.

The next subsection discusses concealment of HIV status in relation to published literature.

6.3.2 Concealment of HIV status

The present findings add a new dimension to the existing body of knowledge on communication about HIV status by illustrating that concealment, generally referred to as non-disclosure in the literature (Jasseron et al., 2013; Manning, 2013; Sullivan et al., 2013; Ueno & Kamibeppu, 2012) is not just about withholding information regarding one's sero-status. Concealment involves very deliberate and targeted efforts to prevent certain individuals from learning about the concerned person's positive HIV status or other stigmatized conditions, such as mental illness (Pandya et al., 2011; Ueno & Kamibeppu, 2012). The affected participants were thus in a constant state of alert with their social contacts, making ongoing decisions about whether or not to conceal their condition. In contrast, non-disclosure of HIV status refers to lack of communication about the underlying infection.

The findings supplement previous knowledge that a perceived lack of need to discuss one's HIV status justified concealment (Gaskins et al., 2011). The present participants were on successful treatment and did not exhibit any obviously discernible HIV symptoms that could raise suspicions about their health. Those concealing their condition were able to do so by presenting a normal, healthy self, while concealing their underlying disease, thus presenting what they believed to be a socially acceptable self. For instance, some of the participants did not reveal their disease to family members in their countries of origin, even when they visited their relatives. Such respondents justified their decisions based on the perceived inability of those family members to provide any support and to suspect that the participants were infected, because they 'looked very healthy'. As discussed in the findings chapters, HIV had stereotypical symbolic markers that identified those perceived to be infected in the participants' native countries, such as severe weight loss, or

physical wasting (Larkan, 2011). The lack of such markers therefore enhanced concealment efforts. However, the present findings also suggest that concealment might be a means of avoiding the psychological and emotional stress involved in narrating one's sexual past to family members and others in their social networks. Those who resorted to concealment therefore avoided immediate social challenges, such as the risk of rejection or stigmatization by family members, but faced a long-term risk of exposure because they created a false social position which they were forced to maintain until they were ready to reveal their status. These findings are similar to those reported in research into other stigmatized conditions such as mental illness (Ueno & Kamibeppu, 2012), where concealment may be used as a strategy for avoiding painful past experiences.

The present study findings illustrated concealment of HIV status from significant others including some family members and friends. Concealment from friends was framed in terms of preserving friendships, since the relevant participants did not want to sabotage the few friendships they had in the UK by revealing their disease. Similar findings were reported by Calin et al (2007), who observed that Black Africans living with HIV in the UK were likely to conceal their sero-status from friends. Although 42% of the 45 respondents in Calin et al.'s study originated from East Africa where all the present participants originated from, the present study respondents were predominantly men (67%) whereas Calin and colleagues' participants were mainly women (69%) from Sub-Saharan Africa in general. Unlike Calin et al.'s study, the present study found gender differences in concealment of HIV status. Men were more likely than women to conceal their HIV status from their family members and friends. Also, the present participants were recruited from community organisations, whereas Calin et al. recruited their participants from an NHS HIV clinic, yet both sets of findings reported widespread concealment of HIV status from friends. This suggests a potential generalizability of the present findings across the study population. However, the present findings also showed openness about one's HIV status by four participants, as part of their involvement in HIV awareness activism to de-stigmatize the disease, as discussed under disclosure above. Due to the uncertainty created by their decision to conceal their status and the constant risk of exposure they faced, some male participants believed their

wives/partners discussed the men's HIV status with their friends. Ironically, some of the accused women never revealed even their own status to the friends they were suspected to have told about their husband's/partner's HIV status. Thus, the desire by some participants to conceal their HIV status from their limited friendship groups, led to social challenges for them through avoidance of certain individuals or social interactions which they believed would leave them vulnerable to exposure. A social activity such as hosting friends in one's house could become a rigorous, stressful chore that involved judiciously hiding any HIV-related resources from sight and monitoring one's speech and interactions to ensure that their HIV status remained concealed.

Consistent with findings by Dageid, Govender & Gordon (2012), the present findings also indicated that some participants concealed their HIV status from parents, especially fathers, with male participants being more likely than females to conceal their status from parents in general. This highlights further gender variation in both who is concealing their HIV status and who it is concealed from. Interestingly, similar numbers of male and female participants concealed their HIV status from their fathers, yet culturally one would suppose that communication about sexual matters was easier within, rather than between genders among sub-Saharan African communities. However, this finding is consistent with the findings of a review of previous studies on HIV status disclosure (Obermeyer et al., 2011) which reported a general concealment of HIV-positive status from men. It is therefore less surprising that male participants were less likely to disclose their HIV status to their male children. The findings support previous research (Casale, 2011) which suggests that mothers in most African cultures play an important role of providing psychosocial solace to ensure their family's survival during adversity, unlike fathers who are expected to cater for the family's material needs (Richter & Morrell, 2008). A possible explanation for concealment of sero-status from parents is the distance between participants and their parents. This finding is consistent with reports in previous literature (Tsai et al., 2013) showing that less physical interaction between the infected individual and their social contacts encourages concealment of HIV status. Some of the participants, for instance, had not seen their family members in their native countries for over a decade and found it hard to effectively carry out a

risk-benefit assessment of revealing their condition to such family members, thereby opting to conceal it rather than risk rejection.

Unlike some previous studies (Dageid et al., 2012; Grant et al., 2013; Linda, 2013) which focused on settled communities within their native locales, the present study involved transnationals, whose other family members were mainly based in their native countries. Those family members' perspectives on HIV were informed by the cultural contexts of the settings in which they resided, where there was inadequate HAART provision, unlike in the UK. But the participants' perspectives of HIV and their responses to it were informed by a hybrid of social and cultural contexts in the UK and in their native countries. The resultant differences in what being HIV-positive meant for the respondents and their family members in their native countries made disclosure to parents potentially more challenging than concealment. Some of the participants justified concealment of their HIV status from their parents and other family members on the basis of the perceived inability of the parents to provide psychosocial and financial support due to distance and economic hardship. This finding is consistent with previous research (Kadushin, 2000) which showed that perceived barriers to support from parents enhanced concealment of HIV status from such parents. Although some literature reports that parents might be shocked by the news of their children's positive HIV status yet remain supportive (Visser et al., 2008), the present findings showed that the concerned participants believed their parents would be too frail to deal with the shock of HIV disclosure, a reaction exacerbated by widespread HIV stigma in the participants' native countries, as discussed in the literature review. Furthermore, the findings illustrated the challenge of discussing one's sexual history with parents, whose potential responses could not be predicted without risking irreversible disclosure. Concealment was thus meant to avoid causing perceived unnecessary stress to parents and other social contacts who would be of little help to the concerned participants, while at the same time protecting those participants from the stress of narrating their life stories to their parents. These findings bear similarities to the theory of awareness contexts identified by Glaser and Strauss (1965), which focused on the influence of awareness on interactions between the dying and their relatives and carers.

Although Glaser and Strauss' analyses focused on impending mortality, their work has relevance to other social contexts, such as communication about stigmatized conditions like HIV-positive status. The present study has shown that family members respond differently depending on their awareness of an HIV-positive diagnosis in the family, and wider social contacts. In Glaser and Strauss' study (1965), family members responded differently based on their information about the impending death, and the known or perceived awareness of the dying individual. Glaser and Strauss identified open, closed, suspicion and mutual deception awareness contexts. In open awareness contexts, common among cancer patients (Seale, Addington-Hall, & McCarthy, 1997), both the patient and those interacting with them are aware of the impending death. Where there is closed awareness, the dying patient is unaware of their impending death. With suspicion awareness, the patient only partially suspects that significant others are aware of their impending death and the relatives' grief, for example, is hidden from the sick individual (Glaser & Strauss, 1965). Lastly, mutual pretence awareness refers to when both the patient and their social contacts recognise each other's awareness of the impending death, although it is not openly discussed. In the present study, the relevant participants were only communicating what they wanted their parents to know, while assuming that the parents were unaware of their HIV status, an example of a closed awareness context. However, the findings also suggested cases of suspicion awareness brought about by a risk of exposure. As discussed in Chapter 5, regarding exposure, some parents suspected their children had HIV but did not reveal their knowledge to the participants, who were also suspiciously concealing their HIV-positive status from their parents.

A key finding was the widespread concealment of HIV status from children. Consistent with previous research into stigmatized conditions (Chew, Beng, & Mun, 2012; Madiba, 2013; Nam et al., 2009; Qiao, Li, & Stanton, 2013; Qiao et al., 2012; Zhou et al., 2012), concealment from children is common and complicated because it involves concealment of not only parental HIV but also, in some cases, concealment of the HIV status of infected children, including those receiving treatment but who are unaware of their illness. However, the present findings are different from most previous studies because they reflect a cultural divide between

the adult respondents and their UK raised children. Whereas the participants hailed from settings where parents were culturally perceived as the bearers of knowledge and controllers of communication about sensitive issues in the family,; some of the children in this study grew up in the UK, were culturally aware of their right to information and able to access multimedia sources of information through which they could learn about HIV. As the findings illustrated, some parents might have incorrectly assumed their children's ignorance of HIV, thinking they were concealing their HIV status from children who were, in fact, fully aware of the concerned parents' disease and who were also managing their own concealment of their discovery. This suggests a mutual pretence awareness in which each party conceals their own knowledge and assumes the other party's lack of such knowledge, again highlighting the relevance of the theory of awareness contexts identified by Glaser and Strauss (1965) to HIV-positive status as a stigmatized condition. For example, some of the participants said that their children had access to the parent's medication but that they refused to explain what it was for, ignorant of the fact that the children could look up the information on the internet if they wanted to. These parents believed that their children, mostly in their teens, were too young to be told about HIV. They framed concealment from children in terms of protecting them from harmful information (Heeren, 2011) and related risks such as stress, shock, stigma and information overload.

Although some participants applied concealment of HIV status with young children, there was no indication of the appropriate age at which to reveal HIV status. In some cases, teenagers and children in their twenties were yet to be told about HIV in the family, a finding consistent with previous studies in different social contexts (Calabrese et al., 2012; Heeren, 2011; Heeren et al., 2012; Krauss et al., 2013; Letteney, Krauss, & Kaplan, 2012). These authors found widespread concealment from children of HIV status and other stigmatized conditions on the basis of young age. One participant argued that telling the children about parental HIV status would only confuse them because, in his view, the children would not comprehend that the parents could be ill whilst appearing normal. Another participant noted that it would only become necessary to tell her children she had HIV if she became very ill, reasoning that if she died her children would know the cause of her death; and that

otherwise, there was no need to reveal her status, hence concealment became a strategy. As previously reported (Gaskins et al., 2011; Obermeyer et al., 2011), concealment becomes a strategy of choice when there is perceived to be a lack of need to disclose one's HIV status. Widespread concealment from children posed communication challenges for families in this study. For instance, some of the affected parents said they were regularly ill, but they could not tell their children why they were on medication or what they were suffering from, even though in some cases the children were heavily involved in their medication routines, as reminders, or helping to fetch or safely store medications. The secrecy by such parents thus led to suspicion among the children and increased the risk of exposure of family members' HIV status through the children's suspicion. Similarly, Ueno and Kamibeppu (2012) noted that lack of information about parental mental illness often leads to anxiety and confusion in children who can tell their parents are ill, but not why or what the parents are suffering from. A service provider who took part in this study noted that concealment of HIV status from children could result in strained family relationships. They cited a case in which an infected child learnt of their condition and strongly resented the parents' decision to conceal the truth. In this instance, the concealment was compounded by the participants' cultural background, which limited their ability to discuss issues related to sexuality with children, particularly those of the opposite gender.

Another key finding was that concealment does not guarantee confidentiality of a stigmatized condition, but rather creates a constant risk of exposure. Despite the effort involved in concealing an invisible stigmatized condition such as asymptomatic HIV-positive status, exposure is an ever-present threat which, if it becomes a reality, negates the sacrifices made by the sero-positive person, such as forsaking potential sources of social support in order to maintain confidentiality. As discussed above, those with a stigmatized condition cannot discover who else already knows about the concealed status without risking revelation. Some participants suspected their status had been revealed but they could not confirm who might have exposed them, if it was one of the people who knew about their condition, or to whom they had been exposed. Concealment, while intended to retain control over the sharing of confidential information, thus leads to loss of

control. The findings showed that affected respondents were constantly on edge with those they were concealing their status from, such as their children, parents, siblings, other family members and friends; and were constantly making decisions and judgements about whether or not they should conceal their status. Although concealment of one's HIV status is blamed by health promoters for hampering HIV prevention efforts and for perpetuating stigma (Obermeyer et al., 2011), the present findings indicate that the decisions surrounding concealment and the subsequent efforts to conceal one's status are complex emotional experiences. Unlike non-disclosure, which merely refers to retaining information, concealment is not likely to hamper HIV prevention because it involves careful risk-benefit analyses requiring consideration of the risk of onward transmission. This may explain why all the participants had revealed their disease to their sexual partners. The next subsection considers exposure of HIV status.

6.3.3 Exposure of HIV status

Unlike previous research which uses 'unintended' or 'secondary disclosure' to refer to unwanted revelation of HIV status,(Qiao et al., 2013; Qiao, Li, Zhao, et al., 2012) the present findings indicate that the term 'exposure' more appropriately explains the concerted efforts by some participants to avoid being uncovered or exposed. The HIV status of asymptomatic participants will remain invisible unless their status is exposed, as discussed below. The term 'exposure' is therefore a notable contribution of the present study to the existing body of knowledge on communication about HIV status. The present findings illustrated that exposure, the perceived and unwanted disclosure to others of a person's HIV-positive status, was a great concern for some of the HIV-positive research participants, particularly where HIV stigma was layered with other stigmatized attributes. Unlike unintended or secondary disclosure, which may be of less concern to the participants, exposure was an unwanted revelation of one's HIV status and a major concern for those who selectively concealed their condition from certain individuals due to a high risk of revelation to an unintended third party. However, the findings also illustrated that there were exceptions to concerns about exposure. Four of the participants were happy to reveal their status to anyone they interacted with, offering an alternative

approach to selective disclosure and concealment as a means of dealing with HIV stigma.

The present findings are consistent with those from research by Madiba, (2013) and Tsai et al., (2013) which indicates that HIV stigma is the main cause for concern about HIV status exposure. However, in the current era of HAART, especially in rich nations such as the UK, HIV stigma can be minimised at the individual level. All 17 HIV-positive participants had access to potent treatment and, as long as they remained on successful therapy, did not exhibit any of the discernible signs of HIV that could lead to outright stigmatization. However, as noted by Engebretson (2013), individuals with 'non-discernible blemishes' may be readily discredited when the information about their concealed condition is eventually uncovered, hence the fear of the constant risk of exposure by some of the participants. HIV stigma was therefore an imminent danger not only because the relevant members of the study population were infected, but because of the risk of exposure of an otherwise hidden attribute, for individuals with several other stigmatized and discernible attributes to deal with, such as membership of a marginalized population group.

The findings showed that those respondents concerned about exposure managed their concealment efforts differently in different social settings. One participant described how she hid her medications from her social contacts in the UK but freely took the medications in the presence of her family members whenever she visited her relatives in her country of origin because of her perceived low risk of exposure to the said family members. This finding suggests risk perceptions vary with perceived differences in awareness about anti-HIV medications between the social contacts in the UK and countries of origin. Moreover, the relevant participants did not have AIDS-related clinical attributes stereotypically associated with HIV in their countries of origin, such as unexplained severe weight loss (Mojumdar et al., 2010). The medications therefore did not symbolise HIV for the participants' social contacts in their native countries. One participant noted that she told her relatives that her medications were sleeping tablets. However this finding could also highlight pretence awareness (Glaser & Strauss, 1964). The relatives might have presented an ignorant self as a way of supporting their ill relative, but such participants could not test their family members' knowledge without risking their confidentiality. The

finding also illustrates the relevance of symbolic interactionism in this study, showing how the affected participants' social contacts drew different conclusions about the medications in the UK and in Africa. Thus, exposure risk perceptions significantly differed between the participants' varying social settings, eliciting different sets of responses relevant to each setting.

The present findings illustrated the risk of losing control over the information regarding one's sero-status as more and more people learn about it. A participant lamented that clinicians exposed his HIV status to his partner without his consent, arguing that it should be left for him to speak to his partner, regardless of his health status at the time. Although the only reported example of a perceived breach of confidentiality by clinicians, this finding highlighted the challenges regarding whose right it is to reveal one's HIV status, and the ethical and moral dilemma faced by clinicians striving to reconcile the conflicting principles of maintaining personal confidentiality against ensuring public wellbeing. This breach of confidentiality, possibly done to protect the participant's partner, was interpreted by the participant as exposure. Whereas Chan (2013) argued that doctors have a duty to breach confidentiality for the public good, the present finding illustrated that to the HIV-positive individual, such action is perceived negatively. Poulton and Anderson (2013) and Phillips and Poulton (2013) pointed out that a breach of confidentiality is only justifiable in exceptional cases and as a last resort, where there is an obvious risk to known parties such as sexual partners, after all other efforts to persuade the infected individual to reveal their infection to the person at the perceived risk of infection have failed.

Another key finding was the gender variation in perceived exposure. HIV-positive men were more likely than women to report experiencing exposure. This was related to the present study finding that male participants were more likely than the women to conceal their infection, elevating the risk of exposure. This is consistent with previous studies (Przybyla et al., 2012; Vu et al., 2012) which also found that men were more likely than women to conceal their disease from their family members and friends. The loss of control that resulted from selective disclosure and the risk created by selective concealment made such men worry about the risk of exposure.

6.3.4 The relevance of the theory of communication about HIV status to other stigmatized conditions

This section discusses the relevance of the present findings to other stigmatized conditions. As discussed above, the findings showed that the present participants managed communication about their HIV status, or, in the case of the HIV-negative participant, the status of their family member, through open disclosure or selective disclosure and concealment. Four of the participants were happy to reveal their HIV status to all their social contacts, whereas the rest selectively revealed or concealed their status, while constantly facing risk of exposure to unintended individuals. The findings supplement previous research by Obermeyer et al., (2011) which suggested that a minority of individuals living with HIV revealed their infection to all their social contacts, including family members, as part of their commitment to HIV awareness and confronting HIV stigma. In psychiatric care, such individuals have been referred to as mental health champions. These are people who have overcome their personal difficulties and use their experiences to improve the lives of their peers and their communities (Missouri Mental Health Foundation (MHF), 2013).

However, stigma is a socially and culturally entrenched process which, according to Young et al (2013), leads to experiences or perceptions of stereotyping, devaluation and discrimination. For instance, the communication challenges discussed above could also apply to cases of leprosy in developing countries where the disease is still highly stigmatized. In developed nations such as the UK, where leprosy has effectively been eradicated through accessible and potent treatment, such stigmatization is unlikely (Roosta, Black, & Rea, 2013). Gambling addiction (Henrietta & Sanju, 2011) is another stigmatized attribute with societal variation, which is more commonly stigmatized in the developed nations compared with poorer nations. Likewise, obesity is highly stigmatized in richer nations, with severe psychosocial consequences for the sufferer (Puhl & King, 2013), just as with HIV. However, in sub-Saharan Africa, a bigger body size symbolizes good health, making obesity less stigmatized. The variation in stigma severity attached to the same condition in different societies underscores the relevance of symbolic interactionism in this study. As Blumer (1969) noted, people make meanings and act upon those

meanings based on their interactions with their environment and their understanding of such interactions. According to Chapple et al. (2004), the stigmatization of a disease depends on whether the person is seen as responsible for the disease or whether the disease leads to disfigurement, disruption of social life and lack of control. Thus, obese or HIV-positive individuals, save for perinatally infected children, may be stigmatized as being responsible for their conditions; whereas cancer patients may be stigmatized because of their physical 'abnormalities' such as hair loss (Rosman, 2004) and their potential imminent death. Even among cancers, Johansen et al. (2013) noted that people are more sympathetic to breast cancer sufferers but stigmatize lung cancer patients (Chapple et al., 2004). Consistent with some HIV transmission routes, smoking as the main risk factor for lung cancer is viewed as an avoidable lifestyle choice. HIV is more stigmatized than other stigmatized conditions such as mental illness or obesity (Puhl & King, 2013). However, advances in knowledge about HIV transmission and treatment have helped to minimise risks of infection, thereby reducing fear and stigma, particularly in richer nations such as the UK and USA. Furthermore, the originally anticipated mass HIV mortality has not occurred. This has led to altitudinal changes towards HIV as signalled by the 2013 lifting of the long standing ban on HIV-positive NHS staff from performing surgical procedures previously deemed to carry too high a risk of transmission to patients (Elliot & Lazenbatt, 2005). Likewise, the blanket ban on all MSM from donating blood was lifted in 2011 for MSM who have not had oral or anal sex for at least 12 months (NHS, 2012) because the total ban was found to be potentially a breach of equality legislation and because improvement in HIV knowledge indicated that the risk of HIV actually reaching the blood pool was minimal (DH, 2011).

Previous studies into mental illness (Idemudia & Matamela, 2012; Pandya et al., 2011; Ueno & Kamibeppu, 2012) and cancer (Henderson et al., 2002; Johansen et al., 2013) have all reported challenges regarding disclosure of the illness to the family members and social contacts of the bearer of the condition. Ueno and Kamibeppu (2012), for instance, found that their sample of Japanese mothers with mental illness generally believed that their child's age was a determinant of whether or not they disclosed their illness, with many preferring to tell older children but not

younger ones. However, consistent with the present research findings, there was no clarity on the age at which disclosure became appropriate Heeren (2011) observed that disclosure of HIV status to children in developing countries seemed to depend on the child's age and the desire to shield the child from harmful information. But Heeren also noted that that the view that children were too young and needed protection from harmful information, such as HIV infection in the family, was less common in contemporary developed societies, where disclosure of such information was viewed positively for the child's development.

The present findings have illustrated that some HIV-positive individuals delay disclosure, or conceal their HIV status, until they believed it was both safe and necessary, with minimal risk of rejection and stigmatization. Similarly, some studies have reported delayed disclosure of other stigmatized conditions. A study into disclosure of child sexual abuse in the USA (Schaeffer et al., 2011) found that adult victims of sexual abuse delayed disclosure of their status because of diverse reasons, such as the personal struggles to come to terms with the abuse, cultural barriers and the uncertainty regarding the responses of the potential disclosure recipients. Just as with epileptic patients who remain 'normal' as long as they control their seizures using antiepileptic medications (Scambler, 2009), the present participants did not exhibit any obvious HIV symptoms and were able to avoid HIV stigma as long as their condition remained unknown. However, the findings illustrated that individuals with concealed stigmatized conditions can never guarantee their confidentiality and manage a constant risk of exposure. The next section considers the strengths and limitations of the present study.

6.4 The strengths and limitations of the study

This section discusses the main lessons from the present study that could inform future research in this area. The strengths of the present study are outlined first, followed by discussions of the limitations of methods and sampling.

6.4.1 Study strengths

The plausibility of the present findings are underpinned by a number of key strengths of the study, as outlined here and subsequently discussed in detail. The study involved a 'hard to reach population' (Braid, 2001), with numerous health and social care needs. Understanding their concerns was therefore vital for public health in the UK, as discussed in the introductory chapter. The use of a modified grounded theory approach enabled the exploration of what it actually meant for the participants to live with diagnosed HIV, leading to the emergence of the theory of communication about HIV status. As discussed under methodology, the grounded theory approach encourages sensitivity to respondents' concerns and allows studies to evolve based on the emerging theory. This approach thus enabled these participants to discuss only what mattered most to them, and what they were happy to share. As the theory developed, the questions used in the interview guide evolved from general concerns regarding daily life with HIV, to concerns about communication of HIV status. The study included five women, partners to five of the 12 men interviewed, which allowed comparison of the perspectives of family members, including important gender comparisons on the meaning of family life with HIV. For instance, the discussions on disclosure in Chapter 3 illustrated that HIV-positive female participants were more likely than the males to reveal their HIV status. As a Kenyan immigrant, the researcher had extensive knowledge of the dual cultural contexts of the study and shared common cultural background with some of the participants. He is familiar with British culture, having studied, lived and worked in the UK for five years prior to the study period. The researcher has worked on national HIV and sexual health programmes targeting Black Africans, MSM and young people in England. London, the study location, was chosen because there are well-developed HIV services and high numbers of the study population are resident in London.

This is possibly the only study in which the experiences and perspectives of HIV-positive heterosexual immigrant black African men in the UK was the main focus. To compare the perspectives of both negative and positive individuals, a sero-discordant couple in which the man was HIV-negative was also included. Although the focus was on men, the inclusion of their female partners enabled comparison of

gender perspectives and greater understanding of the complex issues facing immigrants living with diagnosed HIV.

The discussions in the methodology chapter showed that the use of in-depth interviews allowed participants to express themselves freely. As Blumer (1969) argued, in-depth interviews, a component of grounded theory, are the most appropriate data collection tool for gathering dynamic data grounded in the participants' socially interpreted meanings. The face-to-face encounters allowed the researcher to gauge the mood and temperament of participants during interviews and to determine the appropriateness of the interview proceedings. Non-verbal cues, such as facial expressions and gestures, provided supplementary data. For example, the general furniture in some of the participants' houses and their general mood when describing their economic circumstances added texture to their narratives about their financial struggles.

The researcher's cultural background and shared experiences with some of the participants as an East-African male immigrant boosted theoretical sensitivity. The researcher's 'insider' perspective enabled him to explore interactions and understand some of the participants' concerns more readily than a researcher from a different background. For example, the researcher was aware of the high prevalence of some cultural practices, such as polygamy, among certain tribes from East Africa. It was therefore less surprising when some of the participants from these communities reported multiple sexual relationships, despite their apparent awareness of the risk of HIV transmission. An outsider without prior knowledge of such family constellations might misunderstand the cultural meaning and structure of participants' families when seen out of context. Reference to one's 'children' by adults in the present study population could include any young person under their care, not just biological or legally adopted children as understood in British culture. For instance, one family said they had six children. But it emerged from further enquiry that the couple had two biological children and were taking care of four children from the woman's deceased sister.

The researcher was well-informed about UK culture, the NHS and the historical background of the HIV epidemic in the UK. He had lived in the UK for five years prior to the study, during which time he worked as a health promotion specialist

involved in HIV programmes targeting Black Africans in the UK. For example, the researcher worked on the 2008 national sexual health survey among Black Africans in England (Hickson et al., 2009) and other related research projects (Bourne et al., 2012; Dodds, Weatherburn et al., 2010; Owuor, 2009; Weatherburn et al., 2009). The researcher was therefore able to empathise with respondents' typical concerns such as social isolation, immigration issues and unemployment challenges. As an African immigrant in the UK, with foreign qualifications and work experience, he had personally faced similar challenges himself. The researcher was also aware of the political and policy environment in which the participants lived. Having worked in London as a volunteer mentor supporting failed asylum seekers to access health and social care, the researcher was conversant with the potential challenges some of the participants faced as asylum seekers or failed asylum seekers.

London, with the largest number of community organisations and other service providers involved in HIV-related work with Africans in the UK (Dodds et al., 2008; HPA, 2012a) provided a suitable study location with an excellent opportunity for gaining access to diverse prospective study participants. It is likely that London is the base for the largest population of heterosexually infected immigrant Black African men outside of Africa. Available data showed that over 30% of the 31,147 HIV-positive individuals accessing care in London in 2011 were Black Africans (Forde & Cook, 2013). The researcher has extensive knowledge and experience of the HIV sector in England, knows the organisations to target for participants' recruitment, and in some cases the people to consult regarding potential collaboration. Without such specialised knowledge and experience, it would have taken much longer to establish contacts and gain access to participants, not least because of the confidentiality issues involved in HIV-related services. Further, experience from previous research involving heterosexual Black Africans in the UK has enhanced the researcher's theoretical sensitivity to sexual health matters among this specific population.

The next section reviews the key limitations of the study and the relevant responses.

6.4.2 Study limitations

Despite the strengths outlined above, the study also had limitations which are considered in the following two subsections. The first highlights the methods' limitations, the second considers sampling limitations.

6.4.2.1 Methods limitations

The present study used face-to-face, in-depth interviews for data collection, supplemented by follow-up telephone calls to fill any gaps identified during the data analyses. Member checks were used to validate the researcher's interpretations of the participants' views. The following discussion highlights some pertinent key limitations of face-to-face in-depth interviews.

According to Denscombe (2007), interviews can be an attractive research method because they merely utilise the researcher's innate ability to hold a conversation. But as the present researcher learnt, interviews are more than just a conversation. Interviews require the establishment of a good rapport between the researcher and the interviewees. As Willig (2013) noted, both the researcher and the respondent bring their attitudes, mood and expectations into the research process, which all have to be managed to establish and maintain rapport. Interviews also involve power imbalance, which is common in all human interactions (Nunkoosing, 2005), but means that they need to be managed in an interview process differently from common conversations. In the present case, all the interviewees were older than the interviewer, creating power imbalances that impacted on the interview process in unknown ways. The assumptions the researcher and the participants made of one other's background details, such as immigration status, sexuality, socioeconomic and health status, all impacted on the level of connection that was established. Generally the researcher managed to develop a very good rapport with the participants, enabling them to freely and openly share their perspectives. For instance, he reassured the participants that the study was purely academic and not related in any way to the government or immigration services. In doing so,

immigration risk concerns were minimised, enabling the respondents to freely express their views without fear of reprisal.

The researcher sought the participants' consent to take part in the interviews. However, Willig (2013) argued that a loosely structured interview like the one used in this study, delves into numerous unforeseen and unplanned issues that cannot be consented to in advance. The present researcher therefore urged the participants to share only what they were comfortable revealing and urged them to stop the recording at any point, should the interview progress into issues they didn't want recorded. At the end of the data analyses, the researcher used member checks to further seek the respondents' consent regarding the interpretation of their views. However, as Nunkoosing (2005) argued, ultimately, the reported findings will reflect the researchers' views, which may be influenced by the need to meet the approval of the wider research community, thereby partially superseding the participants' views.

The means used for recording interview data and the knowledge that one is being recorded can affect openness in the interview process. Some of the present participants felt uneasy being recorded, despite the researcher using a supposedly less intrusive digital voice recorder. One participant completely declined to be audio-recorded, prompting the researcher to manually write the responses, as discussed under methodology chapter. In adherence to grounded theory, the researcher also took notes of key issues during the interviews, but this also made some respondents uneasy. This illustrates variations in responses to different means of data recording which, although unavoidable, potentially influences data quality. However, the participants' responses are reactions to the interview interactions, a social process which influences the information the respondents chose to share and the picture they created of themselves, based on their perception of the researcher and the research process. The researcher tried to create the best possible interview environment and judged the participants' responses to be frank, but could not avoid the participants' reactivity. As Charmaz (1995) argued, people choose what part of their life they wish to share at any one point. The voice recording and note taking were thus only supplementary to the reasons for any lack of openness. Since there was no way of counterchecking the participant's narratives to validate them, the

researcher assumed a great degree of openness about the respondents' accounts of disclosure, concealment and exposure of their HIV status. Some limited observation was used during the interviews to note the respondent's body language and home environment, to corroborate the honesty of their narratives. None the less, interviews still remain ideal for exploring sensitive issues such as the focus of this study and for engaging marginalised populations such as in the present study.

The use of face-to-face in-depth interviews, implied that data collection was based on recall of the participants' previous experiences and their perspectives about the study topic at the time. Consequently, the participants' responses represented their retrospective, constructed narratives that confined the resultant analysis to a single point in time and what the participants could recall or were willing to share from their past. A series of interviews in the form of a longitudinal study might have yielded greater variation in participants' perspectives of their life with HIV, since the meaning people make of their circumstances is likely to change over time (Blumer, 1990). Interviews rely on recall, hence theories generated from interviews reflect those concerns that matter most to the participants at the time of the interview, the best-remembered issues and those they are happy to share with the interviewer. The researcher arranged for follow-up telephone calls with all the participants, to illuminate any issues that needed clarification during the analyses, and to check if anything had changed since the initial interviews. The subsequent discussions with those who were contacted over the phone did not highlight any changes in perspectives regarding communication about HIV status.

Despite the above limitations, the present study is in line with other related studies (Krauss et al., 2013; Lee et al., 2013; Madiba, 2013) which have reported challenges regarding disclosure of HIV status, particularly disclosure of one's HIV-positive status to family members, such as rejection and stigmatization and potential loss of social support. The next section discusses sampling limitations.

6.4.2.2 Sampling limitations

This subsection focuses on the limitations of the sampling approach used in this study to access relevant data. The sampling was not intended to be representative

of the wider population (Abrams, 2010), because there is no way of assuming normal distribution of experiences, settings and interactions as explored through qualitative research. The aim of the present sampling was to maximise variation in potential data sources, to form a basis for theoretical sampling. The goals and strategies used for sampling in the present study evolved along with the researcher's familiarity with the data. As discussed in Chapter 2, the methods section, the aim of theoretical sampling is to identify and fill gaps in existing data by further sampling to maximise opportunity to obtain new insights into the data (Lincoln & Guba, 1985).

The initial aim of the study was to explore the range of experiences of living with HIV. But once the theme of communication about HIV status emerged from the data analyses, the researcher ensured that the sampling strategy covered a range of participants' stances regarding disclosure of HIV status from concealment to selective disclosure to common disclosure. Although the generalizability of the present findings is limited, they do contribute to the understanding of a very complex social process involving an equally complex and diverse study population.

The researcher recruited a diverse sample of participants from six community organisations that were willing to facilitate participants' recruitment, from a list of 14 organisations initially contacted regarding potential access and recruitment. Eight organisations originally agreed to facilitate participants' recruitment, but only six were eventually willing to support the study by allowing access to participants. These organisations came highly recommended by leading researchers with an interest in projects involving Black Africans in the UK. This self-selection by organisations might have influenced the responses of the resultant participants in unknown ways. For instance, the organisations might have had a more open ethos on communication about HIV issues, or may have encouraged openness among their service users. It turned out that some of the participants had been involved in previous HIV-related research and the experience might have influenced their responses in the present study. Additionally, the participants were self-selecting, hence the study was possibly informed by those most willing to talk about their concerns, potentially missing out on the insights of those less willing to share their perspectives. Although qualitative researchers acknowledge that some respondents

are more insightful on certain issues than others (Abrams, 2010), the present participants' narratives were insightful in their own right and there was no way of knowing how the perspectives of those who didn't belong to support groups or those unwilling to take part in the study might have differed. The study yielded a range of disclosure strategies that formed the core category of communication about HIV status. The four participants who were open about their HIV status, although outliers (Miles & Huberman, 1994), provided an insightful alternative response to managing communication about HIV status among the study population in which men were less likely to discuss such issues.

The researcher also used a snowballing technique, seeking participants through reference (Martyn Denscombe, 2010), from those who took part in the study to broaden recruitment sources. However, those who were referred were also members of the same support groups as those who referred them. It was not possible to recruit participants through the NHS HIV clinics because of access challenges as discussed in Chapter 2. Recruitment through NHS clinics might have resulted in wider sampling variation, enabling the views of those who were not members of the support groups to be explored. This in turn would have enhanced the generalizability of the present findings. It is possible that the process of engaging participants through peer support groups may enhance self-esteem and encourage sharing of experience and this may have resulted in the present findings reflecting the views of more assertive individuals. Nevertheless, the sampling approach adopted allowed the researcher to identify a range of communication strategies, as discussed in the findings chapters. Fourteen of the 18 participants still concealed their HIV status from certain people outside safer spaces such as HIV clinics and support groups. Although the sampling approach limited generalizability, the researcher considered it to be the best option, because of the sensitivity of the issue explored and the resultant recruitment challenges, as discussed above. The approach allowed for the exploration of a range of accounts regarding communication about HIV status.

The men in the present study also had the opportunity to nominate their wives or partners as potential study participants. This possibly limited access to some informative insights from the women, because the men's views about the research

may have influenced their partners' responses. Crucially, the study was meant to explore the respondents' perspectives and not the validity of such responses. However, the researcher used probing techniques to adequately explore the perspectives of the women during the interviews. As Willig (2013) noted, probing enables interviewees to amplify and clarify their narratives. The relevant women's responses suggested that they were narrating their genuine perspectives, rather than rehearsed responses. For example, one participant seemed to reiterate her husband's narrative about his family's reaction towards her status disclosure. But on further probing, her account added a different dimension to the narrative. Her husband had indicated that his family believed the partner was jealous about his other sexual relationship in his native country. But the woman said that her husband's family stigmatized her and blamed her for infecting her husband, due to high HIV prevalence in her country of origin at the time. She believed her husband infected her and not vice versa. The example illustrates different perspectives on a common concern while providing, a useful contrast in the family unit.

Lastly, exclusion of children for the reasons outlined above was a limitation. The children's perspectives would have contributed to the understanding of how families from the study population manage disclosure and concealment of HIV in the family, whilst minimising the risk of exposure. The next section considers the challenges encountered while carrying out the present study.

6.5 Reflections on the challenges of conducting the study

The aim of this section is to identify and discuss some of the main difficulties encountered while conducting the present study. The discussion will focus on the key challenges related to methodology, access to participants, power imbalance, managing personal feelings and the accuracy of the researcher's interpretation of the participant's perspectives. The methodological challenges considered below include: the multiplicity of versions of grounded theory; theoretical sampling; theoretical sensitivity; the researcher effect on data collection; theoretical saturation; and three-step coding in data analyses.

During the initial literature review to conceptualise the study, the researcher had the impression that grounded theory methodology was an 'anything goes' approach, because of the large number of studies that claim to be based on grounded theory, yet provide no detailed account of the application of the approach (Goulding, 2005) nor specification of which version of grounded theory was used. For instance, some studies claim to use Glaserian grounded theory but report applying axial coding, which according to van Niekerk (2009) is a distinctive feature of Strauss and Corbin's version. The researcher was therefore conscious of the need to avoid adding to such a body of literature. However, the researcher overcame the challenge through extensive reading of key grounded theory texts (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1965, 1967; Strauss & Corbin, 1990, 1998; Strauss, 1987), related publications by the proponents of grounded theory (Corbin & Strauss, 1990; Glaser, 1978, 1992, 2001) and the work of other scholars (Urquhart, 2013; van Niekerk & Roode, 2009; Walker & Myrick, 2006), all attempting to clarify grounded theory and its application.

The researcher struggled to differentiate theoretical sampling from traditional case sampling at the beginning of the study. It was difficult to determine who would provide data relevant to the emerging theory but the difference became clearer after further reading on the topic and through practice during the research process. The key to overcoming the challenge was the realization that in grounded theory, as argued by Adolph, Hall & Kruchten (2008), the population under study was the set of concepts that constituted the phenomena under scrutiny. In other words, it was the concepts that developed the core category of communication about HIV-positive status, rather than the people experiencing the challenge. Theoretical sampling thus guided the questions used in subsequent interviews (Elliot & Lazenbattt, 2005) and the attributes of the subsequent study participants. For example, the researcher asked the initial respondents who, if anyone, knew that they were living with HIV. Initial data analyses suggested a high prevalence of selective disclosure to family members. Subsequently, the researcher asked the participants specifically who in their families knew they were living with HIV, leading to the finding that most of the participants were more likely to tell their sexual partners and siblings, rather than parents and children, as discussed under the findings.

As discussed above, the researcher was familiar with some of the participants' concerns such as stigma, social isolation and immigration status. It was therefore challenging to ensure that the interpretations purely reflected the participants' views and were not a reflection of the researcher's personal experience, for instance difficulty securing employment in the UK or financial expectations of family members in the country of origin. This was particularly evident in the initial interviews when the researcher tended to be drawn into the participants' narratives by saying 'I know what you mean' instead of prompting them to expound. However, this tendency was eliminated through reflecting on each interview session to identify lessons for the subsequent interviews.

It is acknowledged that researcher's common background with some of the participants potentially affected their responses, as discussed above. Although the researcher wanted to explore the participant's realities, how much the participants were willing to share depended on what they made of the researcher's personality, mannerisms, cultural background, social status, gender, age and how comfortable they felt about revealing their life stories in relation to their perception of the researcher. For example, how much they shared would depend on their perceived risk of exposure, because the researcher was also an immigrant Black African who could potentially interact with their own social contacts. The ultimate sample included only the willing participants, whom the researcher successfully reassured about confidentiality. As discussed above, the age difference between the participants and the researcher might also have affected the interview dynamics. In most African communities, sexuality is rarely discussed between adults and younger people (Larkan, 2004), especially between genders. This created an element of reticence in the interview process. For instance, one female participant declined to discuss her views on how she was infected because she couldn't discuss such issues with her 'son', namely the researcher. Cultural sensitivity enabled the researcher to understand and accept the respondent's perspective.

In grounded theory study, data collection continues until theoretical saturation is achieved (Strauss & Corbin, 1990). However, as Bowen (2008) found, determining the point of saturation was a tough feat for the present researcher. The study was a PhD research project, limited to a maximum of four years by the university

regulations. The researcher had to balance achieving theoretical saturation with meeting the study timeline and benefitting from the guidance of a highly experienced supervisory team. A sufficient level of saturation, a point at which no new themes seemed to emerge from additional data, was achieved after 23 interviews, as discussed under theoretical saturation in Chapter 2.

Data analysis in grounded theory involves seeking concepts behind the actualities by looking for codes, concepts and categories (Allan, 2003). At the beginning of the study, it was a challenge determining how to break up the data into fragments and then regroup them into meaningful concepts that would provide new analytical insights leading to the development of the core category. For instance, linking disclosure to, and concealment from, different social groups with the core category of communication about HIV status was initially a challenge. It took a lot of practice and reviewing of the relevant literature on grounded theory data analysis for the researcher to comprehend the expectations in micro analysis involving line by line interpretations as a requirement of modified grounded theory by Strauss and Corbin (Corbin & Strauss, 2008; Glaser, 1992; Strauss & Corbin, 1990).

There was also the challenge of accessing potential participants. 'Gatekeepers' at some of the community organisations, the key personnel who could facilitate access to service users as potential participants, were reluctant to do so. Of the 14 community organisations the researcher approached, only six facilitated participants' access and recruitment. One gatekeeper said that their organisation never engaged their service users in students' research because such studies did not have direct benefits for their service users. The assurances that participants and the agencies involved in the study would get feedback through member checks failed to persuade the individuals concerned. As discussed in the previous section, this recruitment challenge had a potential impact on data quality, because service users from the 'research friendly' organisations had taken part in numerous other studies and their previous research experience could influence their responses in this study. Also, the researcher could not get an NHS organisation to sponsor the study, due to the access challenges and time limitations outlined above. However, a paucity of similar previous research involving black East-Africans made the present study instrumental in uncovering specific issues regarding communication

about HIV-positive status among the study population. The researcher's experience from previous involvement in related studies (A. Bourne et al., 2012; Hickson et al., 2009) enabled him to remain motivated and to continue pursuing further avenues for participant recruitment because he was familiar with the challenge of gatekeeper resistance, and with reluctance to facilitate research-related access to HIV-positive Black African service users.

The present researcher also found some of the participant's experiences uncomfortable. Some of their narratives were emotionally draining, at times leading to emotional breakdown. Two of the men, for example, wept while narrating their experiences with HIV, although, culturally, African men are expected to portray a masculine identity (Dageid et al., 2012). The affected participants regained their composure, completed the interviews and said they did not require further support, which would have been catered for as a part of ethical considerations. The unemployment challenges, unrecognised educational qualifications and work experience from Africa, and the perceived public hostility towards Black African ethnic groups as the face of immigration in the UK (Sinha, 2009) were issues with which the researcher was also personally familiar. Thus the researcher managed a constant risk of 'going native' and losing analytical perspective, because of over-familiarity with the issues raised (Burns et al., 2012), by asking respondents to clarify their narratives whenever necessary, rather than using personal knowledge and experience to transpose his own perspectives onto the participants' narratives. The common cultural background was thus invaluable in understanding the participants' perspectives, but was not used to create such views.

The researcher tried as much as possible to ensure that the views of all the participants were accurately reflected in the findings. The present study found that one of the main concerns for the men and their partners was managing the flow of information about their HIV status. But this finding did not seem to reflect the perspectives of the four participants who had transitioned from selective disclosure and concealment to becoming HIV awareness activists. These participants wanted to inform as many people as possible about their HIV status in order to de-stigmatize the disease and demonstrate that HIV is chronic but manageable with successful treatment. However, the participants concerned had lived with HIV for an average

of 10 years, and had passed through the stage of selective disclosure before ultimately becoming activists. The key finding thus also reflected their perspectives because they had experienced the phase of selective disclosure and concealment of their HIV status. Furthermore, the present findings showed that selective concealment or disclosure, and openly revealing one's HIV status, were alternative communication strategies about HIV status adopted by different participants, depending on their individual situations.

So far, this chapter has reviewed the main findings from the present study in relation to the existing body of knowledge, the strengths and limitations of the study and the challenges the researcher dealt with while carrying out the study. The next section considers the implications of the present findings to policy and practice.

6.6 Possible implications of the research for policy and practice

This section considers the potential implications of the present study findings for HIV related policy and practice involving Black Africans in the UK. As outlined in the introduction to the thesis, the present study population is one of the three key HIV risk groups in the UK, alongside MSM and injecting drug users. The national policy guidelines on HIV prevention involving the study population therefore recommend targeted campaigns aimed at increasing HIV testing uptake and treatment for those who test positive (NICE, 2011), based on the evidence that Black Africans are more likely than the rest of the population to test late for HIV (Fakoya et al., 2008; Forde & Cook, 2013). The literature review chapter illustrated that most previous research involving the present study population focused on HIV prevention, challenges regarding access to healthcare and sexual health needs. But the men and their partners who informed this study had access to treatment and care and did not report any behaviours that suggested they were putting others at risk of infection. The present study thus focused on living with diagnosed HIV, rather than prevention, which didn't enter greatly into the findings, although there were indications of diagnosis being slowed by reticence about coming forward for testing. Consequently, the policy and practice considerations discussed below concentrate

on the psychosocial concerns regarding communication about one's HIV status. The following discussions focus on selective disclosure and concealment of HIV status; open communication about HIV status by community role models; confidentiality concerns; and entitlement to healthcare.

Consistent with some previous research (Obermeyer et al., 2011), the present study demonstrated that HIV-positive individuals selectively disclosed or concealed their HIV status to access health and social care support, and to avoid stigma. However, concealment does not guarantee confidentiality and it creates a constant risk of exposure. The findings showed that many members of the study population found it particularly challenging to disclose their HIV-positive status to their wider family members and friends, partly due to their culture and marginal socio-economic status in the UK, rendering them especially vulnerable to stigmatization. Black Africans, particularly the men, seem to find disclosure of their HIV status a more challenging issue than do others with the same condition, such as HIV-positive MSM. Practitioners and support workers should use this knowledge to help HIV-positive Black Africans think about how they manage disclosure of their, or a family member's, HIV status. Professionals can also enlist the help of HIV-positive individuals who are willing to work as role models, to share their experiences of living with HIV and communicating about their HIV status. Policymakers need to understand the difficulties faced by Black Africans regarding communication about their HIV status, and should continue to invest in support services for HIV-positive or affected Black Africans. In particular, service providers need to help this population to make informed decisions about disclosure of their HIV status, and to manage the consequences of their decisions. One practice implication could be to continue funding psychosocial support and counselling services.

The present findings show that open communication about HIV status offers an alternative that men from the present study population may not accept because they don't want to risk irreversible disclosure. Professionals can discuss this option with HIV-positive individuals from the study population and also draw on the role models of individuals who have 'come out'. The findings showed that four individuals had transitioned from selective disclosure to become HIV awareness activists who were happy to share their experiences in an effort to sensitise others about living with HIV

and confront HIV stigma. This is in accordance with the national guidelines encouraging members of local Black African communities to act as champions and role models to help encourage their peers to take HIV tests (NICE, 2011). However the present findings illustrate that the influence goes beyond merely taking a test. By 'coming out', the role models shape wider societal perceptions about those infected and affected by HIV, as well as changing their own social situations. Policymakers should develop guidelines to ensure an environment conducive to role models feeling sufficiently safe to come out and share their experiences of living with HIV. Return-to-work and workplace policies should also be strengthened so that such 'open' individuals who want to do so, can also engage in gainful employment, rather than merely becoming volunteer activists, to contribute to their overall well-being. This would encourage others who may be considering similar options. HIV-positive individuals now live longer (Zhou et al., 2012) and many may not wish to live a lifetime on benefits, particularly since these have been significantly reduced or abolished altogether.

The challenges surrounding disclosure of HIV status to children has been discussed elaborately in this thesis. Previous reviews of literature on disclosure of parental (Qiao et al., 2013) or perinatally infected children's HIV status (Pinzón-Iregui, Beck-Sagué, & Malow, 2013) found very low disclosure rates to children worldwide. The age of a child was a key determinant of whether the parents revealed or concealed HIV infection in the family. However, the existing body of knowledge does not specify the optimum age for disclosure of HIV status to children, including to children who are themselves HIV-positive. Professionals should continue to support parents or guardians who feel they lack the capacity to discuss HIV in the family with their children. They should also make parents or guardians with HIV more aware of their communication options, as the present findings showed, so that they can make informed choices regarding communication about family related HIV with children. Heeren (2011) noted that, apart from the ethical considerations, there are no national or international guidelines for handling HIV status disclosure to children. Policymakers should develop appropriate guidelines, informed by research, as recommended in the next subsection, which can be used to support parental

disclosure to children. The existing support services that help with disclosure to children need to be strengthened through further funding and support.

The present study findings are consistent with previous research (Phillips & Poulton, 2013; Poulton & Anderson, 2013; Chan, 2013) illustrating confidentiality concerns among those living with HIV across different settings, hence the great concern by some of the present participants about exposure. The findings also corroborated previous literature regarding a perceived tendency among immigrant Africans to gossip about stigmatized conditions such as HIV (Heeren et al., 2012; Kohinor, Stronks, & Haafkens, 2011). This made some of the participants avoid certain services where they were likely to meet people familiar to them from their countries of origin, and who could expose them to their families in their native countries. However, the existence of confidentiality related legislation in developed nations such as the Data Protection Act of 1998 (Office of Public Sector Information (OPSI), 2010) and Health and Social Care Act of 2012 (United Kingdom Government, 2012) in the UK to guard against breach of confidentiality suggests the universality of this human behaviour. Some of the participants, for instance, reported perceived HIV related discrimination or stigmatization by health professionals. Professionals should adhere to confidentiality standards clearly set out in their professional codes of conduct and related policy guidelines to ensure that the confidentiality of the infected individuals is protected, unless there is absolute need for a breach of confidentiality (Phillips & Poulton, 2013). HIV support service providers should be aware that some members of the present study population might not want to use services that serve people from their countries of origin, due to concerns about the risk of exposure. Policymakers ought to monitor the implementation of confidentiality and anti-discriminatory policies to ensure strict adherence by all relevant parties.

Overall, the communication challenges discussed in this thesis call for improvement in HIV awareness across the whole of society, not least to confront homophobia and xenophobia, both of which exacerbate HIV stigma towards the two populations most affected by HIV in the UK. Increased public awareness about HIV will facilitate a favourable environment in which individuals living with HIV can effectively make informed decisions regarding communication about their HIV status with little fear of rejection and stigmatization. Increased awareness may also lead to changes in

practices which have been perceived as discriminatory by some HIV-positive individuals, such as dental services in England (Dodds, 2006; THT, 2011). Sensational media reporting and policy headlines such as *Controlling immigration: regulating migrant access to health services in the UK* (Home Office, 2013) also heighten stigma towards the most vulnerable, such as the present study population, thereby affecting the willingness of those infected to discuss their status.

The next section considers the possible implications of this study on future research.

6.7 Recommendations for future research

This section recommends further research based on the gaps identified in the review of the findings in relation to existing literature and the limitations of the present study. As discussed above, Black Africans are a highly heterogeneous group that tend to be treated in the UK, at least, as a homogenous population with similar experiences and needs. Bourne et al. (2012, p. 1) also point out that much of the previous HIV social research involving Black Africans in England has been survey-based studies focusing on sexual risk behaviours and HIV prevention knowledge. There is a need for further qualitative research to explore the complex array of experiences and perspectives of family life with HIV and the resultant responses by both the infected and affected family members of immigrant Black Africans from other geographic and cultural regions of Africa, such as Southern Africa. There is also a need for similar studies involving other high-risk populations, such as MSM and injecting drug users, to explore family responses to HIV in relation to various HIV transmission modes. In fact, Elford et al (2008) noted that unlike the USA or sub-Saharan Africa, there was limited UK-based research on HIV status disclosure. This implies the need for further research on communication about HIV status, even among heterosexual white British families affected by HIV, to compare how different cultural nuances affect family life with HIV. A related recommendation based on the present study limitations is to consider the merits of paired couple interviews versus individual interviews. There are no known studies using such direct comparisons of couple interviews with individual interviews involving HIV-affected couples in the UK. Paired

interviews in the present study seemed to create unease among some of the participants, potentially limiting how much they were willing to reveal in the presence of each other.

As outlined above, there is little known research involving the HIV-negative family members of HIV-positive individuals from either the present study population or other population groups in the UK. There is a need for further research exploring the perspectives of HIV-negative family members on issues related to a relative acquiring HIV, such as the risk of onward transmission, stigmatization impact, isolation of the entire family and perspectives on prognosis of the infected member. One known previous study by Bourne et al (2012) which focused on sero-discordant couples from the same study population also reported challenges in communication about HIV status.

One key limitation of the present study was the omission of children, as discussed under study limitations above. As the findings illustrated, involving children would have raised confidentiality concerns, since disclosure to children was such a problematic issue for many of the families. For instance, eight of the 12 male participants had children, but none of the men had personally disclosed their condition to their children, even though some of them were known to be HIV-positive. Seven of the men believed their children knew they had HIV through disclosure by their partners or other family members. It was impossible to verify such men's claims because, in the main, their partners did not take part in this study; apart from one, whose narratives illustrated different assumptions regarding the children's awareness of HIV in the family. Her husband believed she had disclosed their HIV status to their children, yet she said she felt unable to tell the children in person. Instead, she took the older children to HIV support services. The younger children, aged 10 and 12 years, did not even know that their parents had HIV, yet the father believed they all knew through their mother. This family case highlights an example of a closed awareness context, as identified by Glaser and Strauss (1965). However, in this case, the HIV-positive individual was aware of his illness and wrongly assumed that the children also knew. Since there was no way of verifying what the two children knew, it could even be a case of mutual pretence awareness. The children's views, discussed in this thesis, are thus constructed

through the gaze of the parents or the service providers interviewed. Future research should therefore explore the children's perspectives on how parental HIV and the children's HIV-positive status, for those living with HIV, affects the family dynamics, especially with regard to communication about HIV in the family. Such future studies should also explore the views of children from HIV affected families from other minority populations in the UK, such as different sub-groups of Asians and Black Caribbean. It is also important to consider the perspectives of children from the 'majority' heterosexual white British families affected by HIV regarding what it means to live in such families. Although research with children would involve complex ethical challenges, they would provide a voice for the children infected or affected by HIV in the UK.

The above review of the present findings and existing literature has illustrated that some parents may have the desire, but felt they lack the skills, to reveal their HIV status or that of an infected child. Such parents instead rely on HIV support services to tell their children about HIV in the family. Heeren (2011) noted a lack of national or international guidelines for disclosure of HIV status to children. There is a need for research to explore the diverse dynamics in children's support groups, such as composition, age of disclosure and children's perceptions about HIV before and after disclosure. Such knowledge would be useful in developing some general guidelines that could be used widely by health promoters to support those parents who may be willing, but lack the skills, to disclose their HIV status to their children. Such a study could use an ethnographic methodology to explore the knowledge and meaning such children attach to HIV and the disclosure process. Additionally, it could play a role in reducing stigma by enhancing communication about HIV in affected families, as well as contributing to HIV prevention by informing decisions regarding disclosure of HIV status to children.

6.8 Summary

This chapter has reviewed the present study findings in relation to existing literature on communication about HIV status. The three major communication strategies which dominated the participants' efforts to control the flow of information regarding their HIV status, namely disclosure, concealment and exposure, have been reviewed. The above discussions illustrated similarities between the present study findings and the previous research findings, and the distinctive contribution made by this study to the existing body of literature. For instance, a case has been made for the term 'concealment' of HIV status as a fitting alternative, relevant to the present study population, to non-disclosure. It has been argued that unlike 'non-disclosure' of HIV status, which merely implies withholding information about one's HIV status from others, concealment involves deliberate and concerted efforts to ensure that specific individuals do not learn of the participant's HIV status. Exposure of HIV status, as a refinement of the existing terminology, has also been discussed as an addition to the existing knowledge on communication about HIV status. Unlike disclosure or concealment, the discussions illustrated that the affected participants had no control over exposure. They could never tell when or how it occurred, nor who knew. Exposure thus led to loss of control over who else could learn of the participant's HIV status. More so, some of the people who were party to this information, whilst concealing it from the infected individuals, could spread it further to other recipients, unknown to the infected person, creating a cascade of exposure and necessitating a strategy of concealment.

The chapter also discussed the relevance of the theory of communication about HIV status developed in the present study to other stigmatized conditions, such as mental illness. However, its applicability to other stigmatized conditions depends on particular social and cultural contexts, because stigmatized conditions and their perceived severity differ between cultural settings. The strengths and limitations, as well as the challenges encountered while carrying out the present study, have also been outlined. This chapter further discussed the implications for policy and

practice; as well as providing suggestions for future research. Although the national policy guidelines on HIV prevention involving black Africans in England focus on testing and treatment, there are contradictory government policies regarding immigrant's access to healthcare, especially those with uncertain immigration status such as some members of the present study population that seem to counteract each other. As discussed above, Black Africans are a diverse population and there is a need for more studies focusing on different subgroups of this group to fully understand what they make of their family life with HIV, and their responses to changes in family dynamics that result from a family member's HIV-positive diagnosis. Further research will inform future policy and practice to best serve the diverse interests of the study population, and will have implications for wider public health.

6.9 CONCLUSIONS

This section reviews the key issues discussed in this thesis. It begins with an overview of the justification and the aims of the present study. It then outlines the methodology and methods adopted in conducting the present study and the key findings. It concludes with recommendations for policy and practice and suggestions for future research.

The introduction of highly active antiretroviral treatment (HAART) has transformed HIV from a killer disease to a chronic but manageable condition by revolutionizing HIV treatment and care. As a result, those knowingly living with the disease and who have access to effective treatment may stay free of major health complications for most or all of their lives, and can now aspire to a normal life span. This is particularly so in resource-rich nations such as the UK, where HAART is freely available.

Improved life expectancy makes the issue of living with HIV increasingly important. However, knowledge about the daily life experiences of those on successful treatment has lagged behind progress in treatment. Much of the extant social science research has been concerned with prevention and, to a lesser extent, the personal impact of HIV on infected individuals. Moreover, many studies have focused on MSM because of the higher prevalence among this group in developed countries; and on women who are more likely to participate in research and are therefore easier to access. There has been limited research on how HIV affects families in the UK, and even less on the experiences of immigrant Black Africans, the UK heterosexual group with the highest prevalence of HIV. The present study was an attempt to address this knowledge gap, and has contributed to the body of knowledge on how HIV-positive members of the present study population manage family life with HIV and how policymakers and service providers could respond to their needs. The research was directed primarily towards Black African heterosexual men, whose perspectives and needs have received little attention from researchers.

The aims of the study were to gain insights into the perspectives of the participants on what it meant for immigrant Black East-African men and their families resident in

London to live with diagnosed HIV; to learn how they coped with their condition; and to develop research-based suggestions as to how services might better respond to the needs of such populations. A grounded theory approach was used because of its suitability for exploring sensitive issues about which little is known. This methodology was underpinned by a symbolic interactionist theoretical perspective which was used to develop an analysis of the negotiated meanings developed by research participants coping with difficult situations for which clear, cultural scripts are not available. The affinity between symbolic interactionism and grounded theory was discussed in the presentation of methodology in Chapter 3.

The researcher conducted in-depth interviews with 11 HIV-positive men and five HIV-positive women, who were partners of five of the men, one HIV-negative man and his partner who was HIV-positive, and five workers from community organisations that offered HIV support services for HIV-positive Black Africans across London. In-depth interviews enabled the researcher to gather rich data on the participants' accounts of living in families affected by HIV.

The interview data showed that 14 of the participants chose to attempt to selectively conceal their HIV-positive status from others. As a consequence, they were constantly deciding whether to disclose or to conceal their HIV status from family members and other social contacts. Whereas disclosure could open up access to social support, it also created a risk of rejection and stigmatization, because the infected individual could not predict the response of their potential confidant in advance. Disclosure was irreversible and led to loss of control over who else learned about the information. It created new risks of exposure because those in whom an infected person confided could decide to pass on the information to third parties, who could in turn tell others, creating potential chains of exposure. Concealment, on the other hand, allowed the person living with HIV to attempt to retain control over information, but it also created the risk of exposure because it increased the number of those unaware of an infected individual's HIV status, and to whom the infected person could be exposed at any given time. Concealment could not guarantee confidentiality because one's HIV status could still be 'given off' through cues such as the presence of HIV medications, or might be divulged by those in whom the HIV-positive person had already confided.

The minority of research participants who had 'come out' publicly attempted to challenge the stigmatization of HIV, and could not be exposed because they were fully open about their condition. The majority selectively revealed their illness to carefully selected confidants while concealing it from others, including members of their families, particularly children, and remaining alert about the constant risk of exposure of their HIV status. Those who had opted for partial concealment chose carefully which support services they accessed and the people they socialised with, and managed any potential clues to their underlying infection in order to try to avoid exposure. The interview material documented the other forms of stress and stigmatization faced by Black Africans who had moved to the UK, including falling between two cultures, insecure residential status and the problems faced by relatives living in their countries of origin. The particular sensitivity of most respondents about their HIV-positive status becoming known to others has to be understood not only in terms of culture, but also in relation to the overall marginality of their socioeconomic status.

Nevertheless, the findings showed that four of the research participants were fully open about their HIV status. They were individuals who had lived with HIV for a number of years and had overcome their fear of stigmatization. They were happy to reveal their infection to their family members, other social contacts and attendees at public HIV awareness gatherings, to use themselves as examples to those who were considering their communication options, and to de-stigmatize the disease. Their choice to openly discuss their HIV status provided an alternative that most men from the present study population may not adopt because of their reluctance to risk irreversible disclosure.

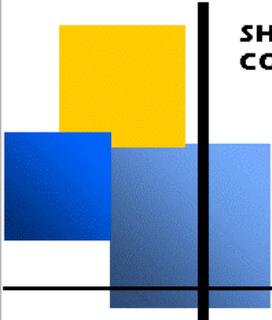
As discussed in the recommendations for practice offered in Chapter 6, professionals in the field can use this knowledge about how the study population, and no doubt many others living with HIV, manage the dilemma of disclosure, in order to help such people to make informed choices. Similarly, policymakers can draw on the findings as evidence of the need to continue investing in support services that help Black Africans and other cultural groups living in developed countries such as the UK to make informed decisions about disclosure of their HIV status, and to manage the consequences of their decisions. However, the Black

Africans living in the UK themselves come from a culturally diverse continent and countries, and this study was only exploratory. There is a need for further research focusing on different subgroups of Black Africans in the UK and for comparative research with other ethnic groups, including those of White British origin. Such work will provide greater understanding of what different people make of their life with HIV, their responses to the changes in family dynamics that result from a member's HIV-positive diagnosis and how services can best serve their needs. The present research focused on heterosexual families in which at least one adult is HIV-positive, a neglected group, on account of them historically not being seen as an epicentre of the disease in much of the developed world. Further comparative research could offer insights into the similarities and differences between their informational strategies and those of the populations living in developed countries who were and still are most at risk, namely men who have sex with men and intravenous drug users.

APPENDICES

APPENDICES

Appendix 1: Study flier



**SHARE YOUR THOUGHTS AND GET £20
COMPENSATION FOR YOUR TIME!**



You can modify the future

Your voice matters!



Are you a man originally from East Africa? You are invited to consider taking part in a study looking at the impact of positive HIV diagnosis on immigrant East African men living in London and their families. The study will involve face-to-face interview scheduled for about an hour at a venue, time and date of your convenience.

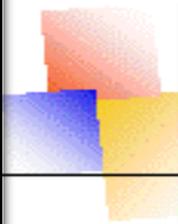
Your participation is completely voluntary and confidential and if you choose to participate, you are free to withdraw at any time.

For more information about the study, please email or text the researcher using the contacts detail below.

John Owuor.
The Centre for Health and Social Care
School of Human and Health Sciences
University of Huddersfield, Queensgate
Huddersfield, HD1 3DH
Email: J.Owuor@hud.ac.uk
Tel: 0782818971



Appendix 2: Response form to invitation to consider taking part in the study



Response to an invitation to consider taking part in the study

**THE IMPACT OF POSITIVE HIV DIAGNOSIS
ON IMMIGRANT EAST AFRICAN MEN
LIVING IN LONDON AND THEIR FAMILIES.**

Please tick the appropriate box that best represents your views.

I am interested in knowing more about the study so that I can decide whether to take part or not. (Please provide your preferred contact details)

Names

Tel.....

Email.....

I am not interested in further information about the study and do not wish to take part in the study.

Please return this form to the researcher using the enclosed stamped addressed envelope that came with the information pack.

Thank you very much for your time.

John Owuor.
The Centre for Health and Social Care
School of Human and Health Sciences
University of Huddersfield
Queensgate, Huddersfield, HD1 3DH
Email: J.Owuor@hud.ac.uk
Tel: 0782818971

Appendix 3: Study information sheet (KCPs)



The impact of positive HIV diagnosis on immigrant East African men living in London and their families

You are invited to consider taking part in a study looking at how an HIV-positive diagnosis affects men of East African origin (from Kenya, Uganda or Tanzania) who are now living in London and their families. The study will provide insights into the issues which such families face, and information about how services might be improved to meet their needs. The families who will be invited to participate in the study will be those in which the man living with diagnosed HIV was born and brought up in East Africa, has resided in the UK for at least one year, and has also been living with diagnosed HIV for more than one year. The men will be living with their wife/partner and children in London at the time of the study. The wife/partner and children may or may not have migrated from East Africa, and may or may not be HIV-positive.

The researcher (John Owuor) is carrying out this study for his Doctor of Philosophy (PhD) degree at the School of Human and Health Sciences, University of Huddersfield. The aim of the study is to obtain better understanding of the needs of immigrant families, particularly those coming from Africa, who are living with HIV, so that services can be improved.

You are kindly requested to take part in a face-to-face interview that will last about an hour. The date, place and time of the interview will be at your convenience. Possible venues for the interviews will include private and confidential meeting spaces at local charities or any other venues acceptable to you that will provide the

necessary privacy and safety. The researcher will meet your travel expenses, and will also provide you with £20 as a token of appreciation of your time.

Your involvement in the proposed study will be purely voluntary, and you will be free to withdraw from the study at any time without having to provide an explanation. You will also have the right to decline to answer any questions. Your access to services will not be affected in any way by your decisions.

During the interviews, I will be asking you about your experiences of living with diagnosed HIV. I will also ask you about your views on HIV-related services and ways in which they could be improved to meet the needs of families in similar situations to yours. The interview session will be recorded, with your consent, using an audio recorder, and later transcribed so that I have an accurate record of your views. Anything that you say will be kept fully confidential to the researcher, and will only be included anonymously in research reports.

After the interview, I will ask whether you are willing for me to invite other members of your family to be interviewed, including your wife/partner and children aged 16+. If you decide to decline, your contribution to the research will still be valuable. If you do agree to me approaching one or more family members, I will ask you to give them some printed information about the study. If this is acceptable to you, I will also provide you with a stamped addressed envelope which those who might be willing to be interviewed will use to get in touch with me. I will be happy to discuss their participation with them, e.g. by telephone, before they decide whether to participate. But I will only contact them a second time if they agree to me doing so. If any family members do agree to participate, I will then arrange to interview them separately at a time and location of their choice, and will reimburse travel expenses in addition to £20 token of appreciation of their time.

All information provided by yourself and family members will be kept completely confidential between the person interviewed and myself, and will only be published in a form which does not allow individuals to be identified by others. Even if you do not wish your family members to be invited to take part in the study, your own

participation would be welcomed. Your family members will also have the right to decline to become involved in the study even though you might nominate them.

I will also be talking to workers from voluntary agencies in London involved in HIV-related care about their general views on the needs of families in similar situations to yours and how they respond to such needs. This will allow me to compare the perspectives of families and service providers. I will not be asking the workers about individuals.

Data from the study will be stored safely in a computer system, only accessible to the researcher through a password system or locked securely in the researcher's University office in accordance with the Data Protection Act of 1998. Some of what you say may be used as direct quotes to emphasise key points that you will raise in the interviews. The researcher will ensure that any direct quotes do not allow you or any members of your family to be identified.

At a later stage, you will have an opportunity to comment on the draft research report and, if you wish, to participate in a feedback, either individually, or via an informal conference which we will invite you to. Please indicate on the consent forms whether you would like to be invited to give us your views about the research findings in either of these ways. If so, I will approach you at an appropriate time.

Participation in the study will involve discussing sensitive personal and emotional issues that might cause you some distress. In case you feel distressed about the issues raised, or need support over other HIV-related issues, you can contact a telephone helpline (Terrence Higgins Trust direct helpline 0845 1221 200, African AIDS help line 0800 0967 500) or look for the nearest counselling and support services from the following link:
<http://www.tht.org.uk/howwecanhelpyou/ourservices>.

You will not receive any direct benefits from taking part in the proposed study other than payment for your time. But the information which you will provide should directly or indirectly inform policies and services aimed at people in similar situations. The

findings will draw attention to the particular needs of immigrants from East Africa who are living with diagnosed HIV. Taking part in the proposed study might also provide an opportunity for you to reflect on your own circumstances. The findings will enable you to learn about how other families cope with HIV.

Although the researcher is not a representative of any government/law enforcement agency, he will be obliged to report any serious health risks, including risks to children, which are not being dealt with to the relevant agency. However, the researcher would only report health related dangers and not immigration issues.

If you are interested in taking part in the proposed study, or if you have any questions, please contact me through the most convenient way for you. You can mail back your response using the addressed stamped envelope provided with this information pack or you can send an email or text message through the contacts below.

John Owuor

The Centre for Health and Social Care
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HD1 3DH

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Tel: 07828182971

In case you have any concerns about the research, please feel free to contact my supervisor directly through the details below.

Professor Bob Heyman

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Appendix 4: Study information sheet

(KCP partners)



The impact of positive HIV diagnosis on immigrant East African men living in London and their families

You have been mentioned by your family member (man who is HIV-positive) as someone we might approach and invite to consider taking part in a research study which he has already contributed to. The study is looking at how an HIV-positive diagnosis affects families living in London in which a man living with HIV originated from East Africa (Kenya, Uganda or Tanzania). The study will provide insights into the issues which such families face, and also information about how services might be improved. The families to be involved in the study will be those in which the man living with diagnosed HIV was born and brought up in East Africa, has resided in the UK for at least one year, and has also been living with diagnosed HIV for more than one year. You don't have to be an immigrant from East Africa yourself to be included in the study.

The researcher (John Owuor) is carrying out this study for his Doctor of Philosophy (PhD) degree at the School of Human and Health Sciences, University of Huddersfield. The aim of the study is to obtain better understanding of the needs of immigrant families, particularly those coming from Africa, who are living with HIV, so that services can be improved.

You are kindly requested to take part in a face-to-face interview that will last about an hour. The date, place and time of the interview will be at your convenience. Possible venues for the interviews include private and confidential meeting spaces at local charities or any other venues acceptable to you that will provide the necessary privacy and safety. The researcher will meet your travel expenses and will also provide you with £20 as a token of appreciation of your time.

Your involvement in the proposed study will be purely voluntary, and you will be free to withdraw from the study at any time without having to provide an explanation. You will also have the right to decline to answer any questions. Your access to services will not be affected in any way by your decisions.

During the interviews, I will be asking you about your experiences of living in a family in which the man and possibly others have been diagnosed with HIV. I will also ask you about your views on HIV-related services and ways in which they could be improved to meet the needs of families in similar situations to yours. The interview session will be recorded, with your consent, using an audio recorder, and later transcribed so that I have an accurate record of your views. Anything that you say will be kept fully confidential to the researcher, and will only be included anonymously in research reports.

All information provided by yourself and family members will be kept completely confidential between the person interviewed and myself, and will only be published in a form which does not allow individuals to be identified by others. You have the right to decline taking part in the study even though you have been nominated by your partner.

I will also be talking to workers from voluntary agencies in London involved in HIV-related care about their general views on the needs of families in similar situations to yours and how they respond to such needs. This will allow me to corroborate the perspectives of the service users like you and service providers to identify any service gaps to be filled.

Data from the study will be stored safely in a computer system, only accessible to the researcher through a password system or locked securely in the researcher's University office in accordance with the Data Protection Act of 1998. Some of what you say may be used as direct quotes to emphasise key points that you will raise in the interviews. The researcher will ensure that any direct quotes do not allow you or any members of your family to be identified.

At a later stage, you will have an opportunity to comment on the draft research report and, if you wish, to participate in a feedback, either individually, or via an informal conference which we will invite you to. Please indicate on the consent form whether you would like to be invited to give us your views about the research findings in either of these ways. If so, I will approach you in due course.

Participation in the study will involve discussing sensitive personal and emotional issues that might cause you some distress. In case you feel distressed about the issues raised during the interview(s) or you need support over other HIV-related issues you can contact telephone helpline (THT direct 0845 1221 200, African AIDS help line 0800 0967 500) or look for the nearest counselling and support services from the following link (<http://www.tht.org.uk/howwecanhelpyou/ourservices>).

You will not receive any direct benefits from taking part in the proposed study, but the information you will provide should directly or indirectly inform policies and services aimed at people in similar situations. Taking part in the proposed study might also provide an opportunity for you to reflect on circumstances. The findings could enable you to learn about how other families respond to life with diagnosed HIV. The findings will draw attention to the particular needs of families where the male partner is immigrant from East Africa who are living with HIV.

Although the researcher is not a representative of any government/law enforcement agency, he will be obliged to report any serious health risks, including risks to children, which are not being dealt with to the relevant agency. However, the researcher will only be reporting health related dangers and not immigration issues.

If you are interested in talking further about taking part in the proposed study, or if you have any questions, please let me know. You can mail back your response using the addressed stamped envelope provided with this information pack or you can send an email or text message through the contacts below.

John Owuor

The Centre for Health and Social Care

School of Human and Health Sciences
University of Huddersfield
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Huddersfield
HD1 3DH
Email: J.Owuor@hud.ac.uk
Tel: 07828182971

In case you have any concerns about the research, please feel free to contact my supervisor directly through the details below.

Professor Bob Heyman
The Centre for Health & Social Care Research
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Queensgate
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HD1 3DH
Email: B.Heyman@hud.ac.uk
Tel: 01484 471124

Appendix 5: Study information sheet (Workers from collaborating agencies)



The impact of positive HIV diagnosis on immigrant East African men living in London and their families

You are invited to consider taking part in a study looking at how an HIV-positive diagnosis affects men of East African origin (from Kenya, Uganda or Tanzania) who are now living in London and their families. The study will provide insights into the issues which such families face, and information about how services might be improved to meet their needs. The families to be involved in the study will be those in which the man living with diagnosed HIV was born and brought up in East Africa, has resided in the UK for at least one year, and has also been living with diagnosed HIV for more than one year. The men will be living with their wife/partner and children in London at the time of the study. The wife/partner and children may or may not have migrated from East Africa.

The researcher (John Owuor) is carrying out this study in partial fulfilment of the requirement of Doctor of Philosophy (PhD) degree at the School of Human and Health Sciences, University of Huddersfield.

You are kindly requested to take part in a face-to-face interview that will last about an hour. The date, place and time of the interview will be at your convenience. Your involvement in the proposed study will be purely voluntary and you will be free to withdraw from the study at any time without having to provide an explanation. You will also have the right to decline to answer any questions that you find inappropriate.

During the interviews, I will be asking you about your views and experiences of working with immigrants, particularly those from East Africa living with diagnosed HIV. I will also ask you about your perspectives on the HIV related needs of the study population and how your services respond to such needs. The interview session will be recorded, with your consent, using an audio recorder and later transcribed into printable copies to enable accurate reflection of your views. Anything you say will be kept fully confidential to the researcher, and will only be included anonymously in any research reports.

Data from the study will be stored safely in a computer system, only accessible to the researcher through a password system or locked securely in the researcher's University office in accordance with the Data Protection Act of 1998. Some of what you say may be used as direct quotes to emphasise key points that you will raise in the interviews. The researcher will ensure that any direct quotes do not allow you or any other informants to be identified.

At a later stage, you will have an opportunity to comment on the draft research report and, if you wish, to participate in a feedback, either individually, or via an informal conference which we will invite you to. Please indicate on the consent form whether you would like to be invited to give us your views about the research findings in either of these ways. If so, I will approach you in due course.

You will not receive any direct benefits from taking part in the proposed study, but the information you provide will contribute to a project which may help you and others to better meet the needs of immigrants from East Africa who are living with HIV. Taking part in the proposed study might also provide an opportunity for you to reflect on your practice.

If you are interested in taking part in the proposed study, or if you have any questions, please contact me through the most convenient way for you. You can mail back your response using the addressed stamped envelope provided with this information pack or you can send an email or text message through the contacts below.

John Owuor
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School of Human and Health Sciences
University of Huddersfield
Queensgate
Huddersfield
HD1 3DH

Email: J.Owuor@hud.ac.uk

Tel: 07828182971

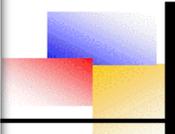
In case you have any concerns about the research, please feel free to contact my supervisor directly through the details below.

Professor Bob Heyman
Centre for Health & Social Care Research
University of Huddersfield
Queensgate
Huddersfield
HD1 3DH

Email: B.Heyman@hud.ac.uk

Tel: 01484 471124

Appendix 6: Interview consent form

<u>Interview consent form</u>	
	The impact of positive HIV diagnosis on immigrant East African men living in London and their families
I have been fully informed of the nature and aims of this research and consent to taking part in it.	<input type="checkbox"/>
I understand that I have the right to withdraw from the interview at any time without giving any reason and a right to withdraw my data if I wish.	<input type="checkbox"/>
I understand that I have the right to ask any questions or raise any concerns I might have with the researcher at any time.	<input type="checkbox"/>
I give my permission/do not give my permission for my interview to be audio recorded.	<input type="checkbox"/>
I give permission to be quoted (by use of pseudonym).	<input type="checkbox"/>
I understand that the audio files will be kept securely at the University of Huddersfield.	<input type="checkbox"/>
I understand that no person other than the researcher will have access to the recording.	<input type="checkbox"/>
I understand that my identity will be protected by the use of pseudonym in the research report and that no information that could expose my identity will be included in any report or publication resulting from this research.	<input type="checkbox"/>
I would like to receive preliminary report, to provide feedback on the study findings.	<input type="checkbox"/>
I would like to take part in a mini conference to be organised to discuss the study findings.	<input type="checkbox"/>
Name of participant _____	
Signature _____	
Date _____	
Name of researcher. John Owuor	
Signature _____	
Date _____	
<i>Two copies of this consent form should be completed: One copy to be retained by the participant and one copy to be retained by the researcher</i>	

Appendix 7: Demographic questions (KCPs)



Q1. I would like to know more, if it is ok with you, about you and your family.

- What is your age?
- What is your country of birth?
- How would you describe your current nationality?
- How long have you lived in the UK?
- What is your first language?
- What is your religion, if any?
- What is your highest level of education? Was any part of your education attained in the UK?
- Are you currently employed?
- What is your current occupation?
- What is your current marital status?
- How long have you been with your current partner/wife?
- What is the country of origin of your partner/wife?
- What is her ethnic background?
- Do you have any children?
- What are the ages and gender of your children?
- How many other people live with you in your household? How are they related to you?
- Including the time you have already spent here, how long do you intend to stay in the UK?
- Do you have plans to go back to your country of origin at some point? If so what are they?
- How would you describe your health in general?
- Do you look after, or give any help or support to family members, friends, neighbours or others because of either:
 - Long term ill health or disability?
 - Problems related to old age.

Appendix 8: Interview guide (KCPs)



Q1. I am interested in finding out what it means to you and your family to live with diagnosed HIV.

- Please describe how you found out you had HIV?
- When were you diagnosed with HIV?
- How long do you think you had HIV before you were diagnosed?
- Who knows that you have HIV?
- Please describe your reactions, and those of family members/friends/others, when they learnt that you have HIV?
- Please describe how you disclosed your HIV-status to your family members, if you have?
- Are there any of your family members also living with diagnosed HIV?
- Could you please describe how your life and those of family members have been affected by your/their HIV-positive diagnosis?
- What are the main issues for you as a man living with diagnosed HIV?
- What do you think are the main issues for your family members arising from your/their HIV-positive diagnosis?

Q2. I am also interested in knowing your views about HIV-related health and social care in London.

- What HIV-related services, if any, do you and your family members use?
- How far do you think that your needs and those of your family members are met by HIV-related services in London?
- In your view, what should be done to improve HIV-related services to meet the needs of individuals and families in similar situation to yours?

Q3. Is there any other thing you would like to add or talk about?

Q4. How did you find the interview?

Appendix 9: Demographic questions (KCPs partner)



Q1. I would like to know more, if it is ok with you, about you and your family.

- What is your age?
- What is your country of birth?
- How would you describe your current nationality?
- How long have you lived in the UK?
- What is your first language?
- What is your religion, if any?
- What is your highest level of education? Was any part of your education attained in the UK?
- Are you currently employed?
- What is your current occupation?
- What is your current marital status?
- How long have you been with the current partner?(in the case of wife/partner)
- If appropriate
 - Do you have any children?
 - What are the ages and gender of your children?
- How many other people live with you in your household? How are they related to you?
- Including the time you have already spent here, how long do you intend to stay in the UK?
- Do you have plans to go back to your country of origin at some point? If so what are they?
- How would you describe your health in general?
- Do you look after, or give any help or support to family members, friends, neighbours or others because of either:
 - Long term ill health or disability?
 - Problems related to old age.

Appendix 10: Interview guide (KCPs partner)



Q1. I am interested in finding out what it means to you and your family to live with diagnosed HIV.

- Have you ever taken an HIV test? What do you believe is your HIV-status?
- Please describe how you found out that you had people who were HIV-positive in your family.
- When was HIV diagnosed in your family?
- How long do you think that your family member [name of KCP] (and you if appropriate) had HIV before diagnosis?
- Who knows that your family member [name of KCP] (and you if appropriate) has HIV?
- Please describe your reactions and that of family members/friends/others when they learnt that your family member [name of KCP] (and you if appropriate) has HIV?
- Please describe how your family member [name of KCP] (and you if appropriate) disclosed your status to your family members, if you have?
- Could you please describe how your family member [name of KCP] (and you if appropriate) has been affected by HIV-positive diagnosis?
- What are the main issues for your family member [name of KCP] (and you if appropriate) regarding family life with diagnosed HIV?
- What do you think are the main issues for your family members arising from the positive diagnosis of your family member [name of KCP] (and you if appropriate)?

Q2. I am also interested in knowing your views about HIV-related health and social care in London.

- What HIV-related services, if any, your family member [name of KCP] (and you if appropriate) use?
- How far do you think that the needs of your family member [name of KCP] (and you if appropriate) are met by HIV-related services in London?
- In your view, what should be done to improve HIV-related services to meet the needs of individuals and families in similar situation to yours?

Q3. Is there any other thing you would like to add or talk about?

Q4. How did you find the interview?

Appendix 11: Interview guide (Workers from collaborating agencies)



Q1. I am interested in knowing your views on the needs of immigrant African men with families living with diagnosed HIV in London.

- Please describe your own role in relation to supporting immigrant African families living with HIV?
- How do you think positive HIV diagnosis affects the lives of the immigrant black Africans accessing your services?
 - What difference, if any, do you think that the gender of those infected makes to their response to diagnosed HIV?

Q2. I am also interested in knowing your views about your services and those of other agencies involved in HIV-related care of the immigrant black Africans in London.

- What are your views about access and use of your services and other HIV-related services by diagnosed HIV-positive immigrant African men in London?
- In your view, what are the issues faced by the families of diagnosed HIV-positive immigrant African men in London?
- How do your services respond to these issues?
- In your view, what should be done to improve HIV-related services to meet the needs of individuals and families from black African communities?

Q3. Is there any other thing you would like to add or talk about?

Q4. How did you find the interview?

Appendix 12: Table illustrating the initial open coding process

Extract	Participant	Initial codes
<p>So how do you make your ends meet?</p> <p>Sir?</p> <p>How do you cope?</p> <p>You know, when you are here. You are not allowed, just, you are allowed just to go for short courses. Because you are not entitled to state benefits, what. So you just go for short trainings like that</p> <p>Yea I can imagine. And if you don't mind sharing with me, how many other people live in your house at the moment?</p> <p>Where?</p> <p>Hmmm.</p> <p>Hesitant, but finally opens up.</p> <p>You know I live in a hotel!</p> <p>Ok</p> <p>This partner is living different. Yea. Because for her, her papers were sorted out some time back. Yea and me I was still waiting. But for me I live in a hotel whereby the social service used the system, which was good: that all people living with HIV we live together in a hotel. So we get an advantage of sharing our problems and there is no stigma around there. Yea. So we live about seven. But each and every person in their own room.</p>	<p>KCP 6</p>	<p>Training opportunities limited – prescribed</p> <p>Doesn't match needs –</p> <p>no recourse to public funds –</p> <p>Restrictions of asylum process. (Page 4)</p> <p>Temporary accommodation – bed and breakfast.</p> <p>Less pride in current accommodation (Page 8)</p> <p>Partner has own accommodation –</p> <p>Sorted immigration opens up services. Page 8</p> <p>Temporary accommodation with peers had benefits:</p> <p>Peers support</p> <p>No stigma. Page 8</p>
<p>What is your current marital status?</p> <p>My partner left some time last year. She could not deal with my situation</p> <p>What do you mean?</p> <p>She said I should sort out myself. You know with HIV you are always depressed, low in mood. Things like that. She said she could not take it. She had her own depression to deal with and so she didn't want to take mine on as well. She wanted to have somewhere to have a good time and not moving from her ward to another ward</p>	<p>KCP5</p>	<p>Relationships break down-</p> <p>Due to HIV-related ill health –</p> <p>Home viewed as ward</p> <p>Different expectations in the relationship</p> <p>Loss of social support.</p> <p>HIV barrier to 'good time'</p> <p>Page 2.</p>

Appendix 13: Table illustrating further open coding process

Participant	Participant statement	Open code
KCP3	At that time	<i>Point in life</i>
	I already knew my status	<i>awareness</i>
	So I told her look here, HIV is not something to worry about	<i>Assertive, comforting</i>
	As long as you stick to you regime	<i>Condition/requirement Pronoun shift</i>
	You can live a normal life	<i>Probability of 'normality'</i>
KCP5	To me now, the main issues is not about HIV really because it is under control	<i>Personal view HIV not main concern</i>
	I am taking my medication	<i>Action taken to deal with HIV</i>
	I have a partner, I am in a steady relationship	<i>Steady social relationship</i>
	I don't have to go out to look for more partners, whereby you to do what, these disclosures (<i>raised tone</i>)	<i>Can withdraw from social scenes, safe from the requirement to disclose status Pronoun shift</i>
	So it is not a big issue to me	<i>Not main concern</i>

Appendix 14: Table illustrating axial coding around category on morality, blame and accountability

Extract	What	When	Why	Consequences
<p><i>First, my husband's people they thought, they were blaming me because I [come from country X, because people from country X] have HIV. May be I am the one who brought it to my husband ... But eventually they just, because of their ignorance they didn't know what was happening</i></p>	Blamed for infecting the husband with HIV	When she was first diagnosed with HIV	Social stigma. HIV linked to country of origin, 'outsider versus us'. HIV and outsider disease Ignorance about HIV	Disclosure of positive diagnosis despite of the blame Denial by husband's family – non-disclosure of HIV status.
<p>It has cascaded, but without me doing it. It is her who did it again. Because when she went, I went with her home, she again reinforced it to my mother and things like that. So she discusses with my mother, but not me. I don't discuss with my mother about this.</p> <p>That is her character. She sort of like, sometimes she wants to character assassinates me or to put things in a different way, u know. But that is her character. I found out she is discussing these things with people like my mother.</p>	Wife discusses husband's HIV status with his family members without his knowledge	Whenever she interacts with his family	Perceived to be her character to talk about HIV. To damage the man's image.	Perceived status exposure, malicious.
<p>Telling it is ABCD, black and white. And it is not easy for me to disclose it, just tell them like that. So it has denied me the right to be free, to be very direct and positive to my, those who want to call me daughter and nice and aunty and all that. Because you feel like ok as we were growing up, this is what you gonna tell them and it is good to tell the truth. For once are you telling the truth? I am not!</p>	Hiding HIV status from family, not telling the truth	In her communication and interactions with family	Challenge of telling family members and other relatives the truth about positive HIV status. Current position conflicting with child family values of telling the truth.	Non-disclosure, blame, guilt

Appendix 15: Memo [(12 April 2011) KCP1]

Support

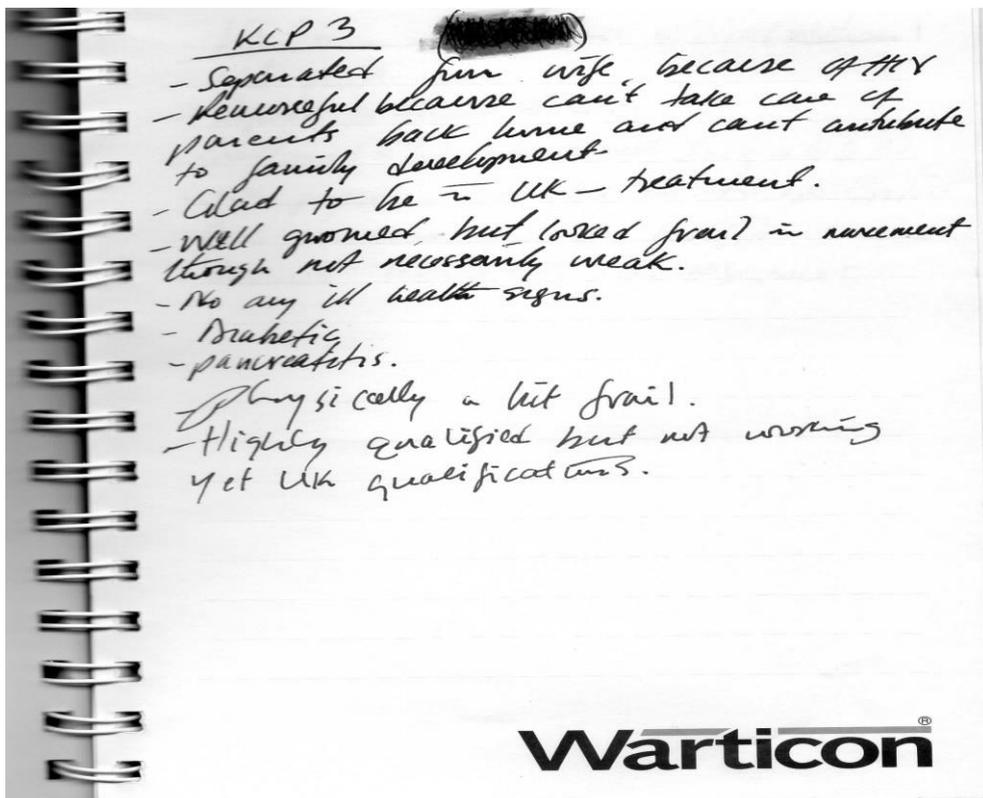
“Family support is very important, very crucial”. Giving or receiving support meant different things for different participants. It was used to refer mainly to people who assisted with access to health care or those who provided accommodation. When participant talked of support, they mainly meant social psychological support. Clinical care was not viewed as support but treatment. Support was linked to disclosure or non-disclosure of HIV status. Participants got support from people who knew they were living with HIV. But sometimes they never got the support they needed. Support also linked to HIV support groups which provide diverse services such as training, feeding programmes, legal advice and career development.

Appendix 16: Sample field notes

Field note: 11 march 2011 (KCP7 & KCP7W)

Participants were married couple. Man was born in Uganda and woman born in Kenya. They have been married for about three years. They met at an LGBT support group function in London. The participants opted to be interviewed at their residence, because of health concerns of their child. The home had basic furniture and the participants seemed very unsettled in what they termed their new residence. They said they had just moved in and were still trying to make it "a home". The property is a flat in a quiet end of a terrace road. Physically, the participants looked well and seemed upbeat in mood. They however expressed various emotional and health concerns during the interview

Field note: 27 January 2010 (KCP3)



Appendix 17: List of organisations contacted to facilitate participants access and recruitment.

1. African Advocacy Foundation
2. African Health Policy Network (African HIV Policy Network),
http://www.ahpn.org/**
3. Body and Soul, <http://bodyandsoulcharity.org/>
4. Cara Trust, http://www.caralife.com/about_cara.html*
5. Embrace Community Support Centre (Embrace UK),
http://www.embraceuk.org/**
6. Enfield Peoples Project (EPP), http://enfieldpeople-project.co.uk/*
7. Naz Project London, http://www.naz.org/**
8. Organization of Positive African Men (OPAM)*
9. Positive East, <http://www.positiveeast.org.uk/>
10. Positive Women, <http://www.positivewomen.org/>
11. Terrence Higgins Trust (THT), http://www.tht.org.uk/*
12. The Harbour Trust**
13. The Rain Trust, http://www.raintrust.org.uk/index.html*
14. Uganda Aids Action Fund (UAAF)**

NB

*Those organisations that facilitated participants' access and recruitment.

**Those organisations that were willing but did not facilitate actual recruitment of participants.

Appendix 18: Demographic details of the KCPs and their partners

Pseudonym	Gender	Age	Country of Origin	Current Nationality	Residence status	Years in the UK	Year tested positive	Years lived as HIV-positive	Where tested
Paul	Male	51	Uganda	British	Permanent British resident	23	2000	11	UK
Robin	Male	45	Kenya	Kenyan	Permanent British resident	23	1998	13	UK
Harmony	Female	48	Uganda	British	Permanent British resident	21	1997	14	UK
Troy	Male	57	Uganda	British	Permanent British resident	20	1999	12	Uganda, Nigeria, UK
Luke	Male	41	Uganda	Ugandan	Indefinite leave of stay	12	2000	11	UK
Dan	Male	49	Uganda	Ugandan	Asylum seeker	8	1999	12	Uganda
Damien	Male	52	Uganda	Ugandan	Asylum seeker	7	2004	7	UK
Lorna	Female	52	Uganda	Ugandan	Permanent British resident	12	2000	11	UK
Bill	Male	31	Uganda	Ugandan	Indefinite leave of stay	11	2004	7	UK
Rachel	Female	37	Kenya	Kenyan	Asylum seeking	12	2003	8	UK
Biden	Male	43	Burundi	British	Indefinite leave of stay	13	2002	11	UK
Melisa	Female	43	Uganda	British	Permanent British resident	20	1998	13	UK
Trevor	Male	47	Kenya	British	Permanent British resident	15	2008	3	UK
Phil	Male	51	Uganda	Ugandan	Asylum seeker	9	2002	9	UK
Millie	Female	54	Uganda	Ugandan	Asylum seeker	5	2008	3	UK
Tyron	Male	45	Somali	Somali	Indefinite leave of stay	9	2004	8	Somalia
Robert	Male	40	Rwanda	Rwanda	Asylum seeker	8	HIV- Ve	0	UK
Lucy	Female	35	Rwanda	Rwanda	Asylum seeker	5	2003	9	Rwanda
Mean	-	46	-	-	-	13	-	9	-
Participants from service provider agencies (All pseudonyms)									
Anne	Female (Black African)								
Oliver	Male (White British)								
Graham	Male (Black African)								
Rose	Female (Black African)								
Peter	Male (Black African)								

Appendix 19: School of Human and Health Sciences Research Ethics Panel (SREP) approval letter



13 September 2010

Mr John Owuor
Research Student
School of Human and Health Sciences
University of Huddersfield

Dear John

School Research Ethics Panel (SREP) Submission

Title of Study: "The impact of positive HIV diagnosis on immigrant East African men living in London and their families: A grounded theory study"

I confirm that your project, as titled above has received ethical approval from the School of Human and Health Sciences Research Ethics Panel, University of Huddersfield.

I also confirm that indemnity for this project will be covered by the insurance policy held by the University of Huddersfield, as it falls within the normal range of research activity.

With best wishes for the success of your research.

Yours sincerely

A handwritten signature in black ink, appearing to be 'Nigel King', written over a horizontal line.

Prof Nigel King
Chair, SREP
School of Human and Health Sciences

Direct Tel: +44 (0)1484 472812
Email: n.king@hud.ac.uk



Queensgate Huddersfield HD1 3DH UK Telephone +44 (0) 1484 422288 Fax +44 (0) 1484 516151

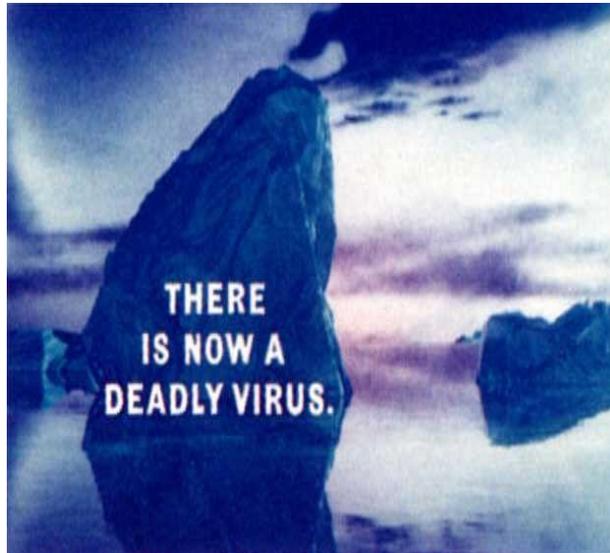
Vice-Chancellor: Professor Bob Cryan BSc MBA PhD DSc

An exempt charity and a centre of excellence for vocational education and research



INVESTOR IN PEOPLE

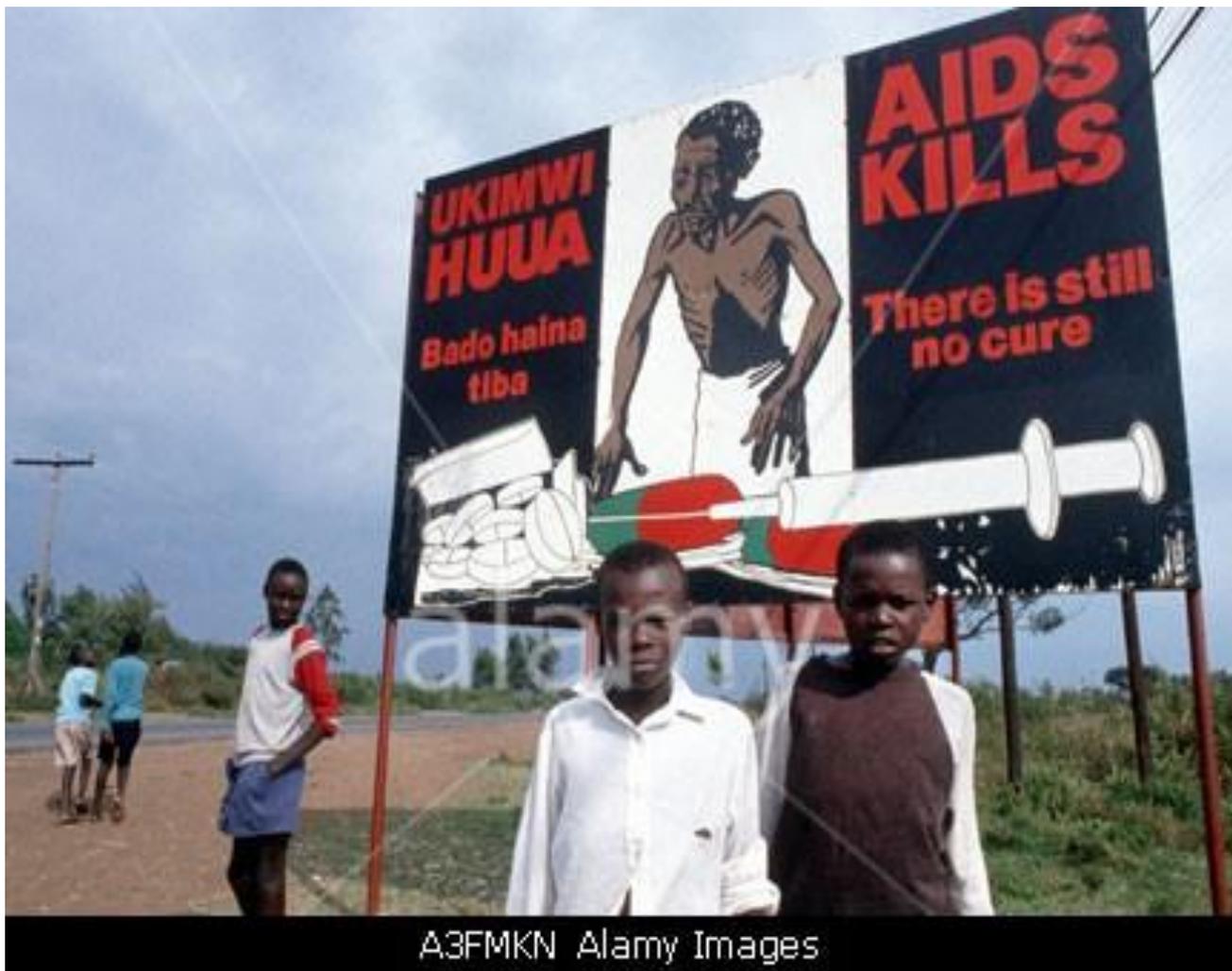
Appendix 20: HIV awareness campaigns imagery used in the UK in the early 1980s



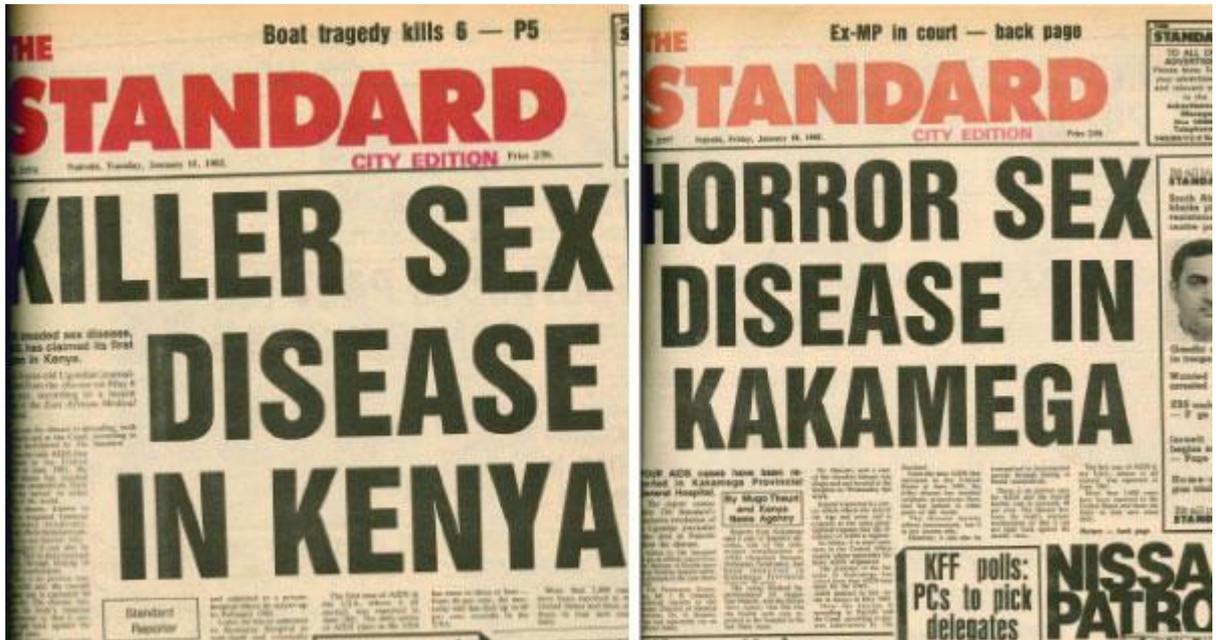
Appendix 21: The Australia grim reaper Aids Campaign of 1987



Appendix 22: HIV awareness billboard in Kisumu, Kenya, in the early 1990s



Appendix 23: Stigmatizing Kenyan newspaper headlines regarding HIV during the early 1980s



Appendix 24: Summary of the main findings for member checks (Page 1)

Background

Black Africans, culturally very diverse, make up just under 1% of the UK population (ONS, 2011) yet they account for a third of all new HIV diagnoses in the UK (HPA, 2012). Although HAART has transformed HIV into a chronic disease (Shacham, Small, Onen, Stamm, & Overton, 2012), HIV-affected families now deal with long-term implications (Taiwo, Murphy, & Katlama, 2010), some previously unknown such as kidney (Scherzer et al., 2012) or liver and bone marrow conditions (Sharma, Tilak, Lodha, Sharma, & Dabkara, 2013). Despite of free access HIV treatment and care, Black African immigrants in the UK are more likely to test late for HIV, with higher risk of morbidity and mortality compared with the rest of the British population (Fisher & Delpech, 2009; Forde & Cook, 2013)



The immigrants arrive to the UK, for various reasons, with diverse aspirations ... and then comes the news; HIV-positive diagnosis! For the study population, the resultant HIV-stigma 'layers' on to other stigmatised attributes such as ethnicity, immigration status and lower socioeconomic standing.

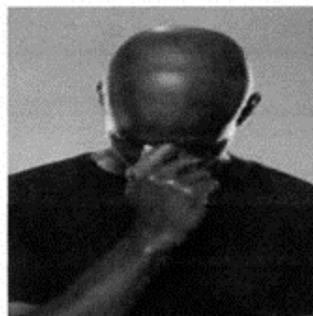
Aim

The aim of the study was to explore the perspectives of immigrant black African men from East Africa, their female partners and workers from HIV-service provider organisations on what it meant for such men and their families to live with diagnosed HIV and how the services in the UK can respond to the needs of such population.

Methods

The study used in-depth face-to-face interviews with 5 sero-concordant couples, 6 HIV-positive men and 5 workers from HIV service-provider agencies in London. To get the

perspectives of HIV-negative family members, a sero-discordant couple, in which the man was HIV negative based on his most recent test, was recruited and interviewed as well.



... the men and their partners carefully chose who, in their UK and African families, to tell about their positive diagnosis ...

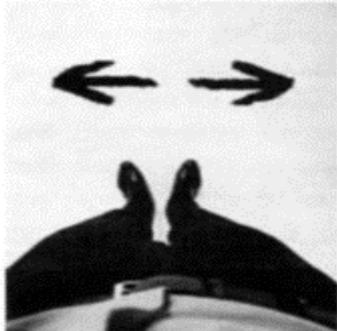
Results

The findings show that the men and their partners were concerned about the risk of exposure of their HIV-status against their wishes, losing control over whom else would know about their diagnosis through a 'cascade of disclosure'. Although they were aware that disclosure of HIV status was a prerequisite for accessing relevant support, many of the participants concealed their condition to retain confidentiality. Apart from four participants who had become HIV awareness activists and were happy to reveal their condition, the remaining thirteen HIV-

Appendix 24: Summary of the main findings for member checks (Page 2)

positive participants carefully chose whom they told about their infection to minimise the risk of exposure and stigmatisation.

The study found that men were less likely, compared to women, to disclose their infection to their parents, siblings and children, and were more at risk of HIV status exposure than women since they concealed it from many of their social contacts. The men also left the task of disclosure of the HIV in the family to the women, even though some of the women also found the task challenging and relied on support services. Fourteen of the seventeen HIV-positive men and three of the six women said their positive HIV status had been exposed to third parties against their wishes at some point in their life with HIV.



... whether the men and their partners disclosed or concealed their infection, they faced constant risk of exposure of their HIV-status

Family responses were found to vary. Children, especially young ones, were rarely told about the HIV in the family, even when the children were themselves infected.

Conclusion

Although the availability of HAART has transformed HIV in to a chronic but manageable condition, communication about HIV-status in the family, particularly in a complex multicultural context, remains a challenge. This inhibits family members' access to and use of HIV services, contributing to continued poor outcomes for immigrant Black Africans, particularly the men. This in turn diminishes the potential of the current Treatment as Prevention (TasP) initiatives. HIV support services are very important for the survival of those infected, but they should expand to include key family members of those infected as well who would in turn provide the infected with vital social support within the families, hence improve communication about HIV in the family. Improving communication about HIV in the family has the potential to reduce HIV-stigma within the families, which would then translate to reduced stigma at the community level. There is also the need to build the capacity of parents and guardians to disclose HIV in the family to children, especially those children living with HIV.

Appendix 25: Sample interview transcript

(Some information removed for confidentiality considerations)

I would like to know more, if it is ok with you, about you and your family.

How old are you?

I am exactly ... years old now. Yes. Ieemm....I was born in.....yes.... I studied in ... and studied in England. And I am refugee..... I came here as a refugee and I have lived in this country for now 23 years. The other issue is that in the course of during that time, I actually had several girlfriends, but now I have one lady who is my wife and I have children and who are now, some of them are grown ups. And I have the last born is now ten years. Now....., so far that is the introduction as far as I am...concerned.

What is your country of birth? And currently what is your nationality. My nationality is still

Still ...?

I am still ...

You have not changed?

I have not changed my nationality. I am still ...

Any reason for holding on to your

No it is just like I am little bit funny. I just didn't like to change to be a British citizen, aahh, for, for very silly reasons which I find that now, I should have changed. But then I was reluctant to change. But my family they are all British.

But I take it that your residence is

Yea I am a resident in, permanent resident in England

What is your first language?

My first language is ... from ...

What is your religion, if any? Christian.

Any specific category within Christianity.

Well, I was born a catholic. But then as years went by, I became biased towards Pentecostal, sort of. I am more leaning towards Pentecostal thinking rather than catholic denomination as it were. Officially I am catholic by denomination.

What is your highest level of education? Was any part of your education attained in the UK?

My highest level of education I would say is Masters. Yea, but, it has been a long road because when I started law in ..., University of Then I became a student leader of ... University. Then I was expelled from University of ... when I was a 2nd year. Then I came to London. I started all over again! From year one at University of London because they could not accept the education I had. Then again I studied law again, so I graduated again with bachelor of laws in London. Then again I went to do my master from University College London. Thereafter, I struggled on to try and practice as a barrister. I went to the bar. But then I could not. Because at that time when I was supposed to go to the bar, you had to have a permanent resident to declare that you are going to practice law in England and Wales, otherwise, you had to qualify to the bar, but you had also to declare that you will never practice law in England and Wales, if you did not have a permanent residence at the time. So, I had to, I had to wait. I had to keep waiting keep waiting doing some jobs here and there. Working voluntary jobs like places like this one (*referring to interview venue*). Until eeh, I got confused a little bit in between. I ended up finding a lady and things

like that. Then family issues, started confusing me and things like that. I went to things like drinking, over drinking and things like that. You know, things like that. So, and then, slowly by slowly, my interest got, when I went back again to do the bar, they tell me, ohh, your degree is now going, still you have to do now another one year CPE, common programme (*not clear*)examination for another one year. And these ones I just got so lazy and I just take paralegal work. So what I have been doing mostly is doing advice work with like, I work with citizens advice bureau, I work as an advocate within settings like this one (*referring to interview venue*). Yea things like that. So I have just been going on like that and forgot about the law.

So currently you do not have fixed employment?

No no.

How long have you been with your current partner/wife?

Eeh, since, eehh, for more than ten years. Since 1989.

What is the country of origin of your partner/wife?

...

You met here or out in Africa.

We met here, we met here.

Do you have any children?

I have two biological children. And eeh, currently I have other children who I am raising up but they are not my children. In other words they are children of the sister of my wife. My wife only has two children, and I also have two children with her. She doesn't have children with any other person. But because the sister died

So the two of you have the two children?

Yes, but the sister died, so we took their four children. So in other words I ended up raising six children. Some of them who have already gone through university and are already settled elsewhere.

How many other people live with you in your household? How are they related to you?

Because they have, there are others who have gone. Like the three old ones have gone. So only about 3 remaining, me and my Mrs.

So you don't have any extended relatives living with you at the moment? No extended relations like, as I have described these ones. The six as I have described them.

No one, those ones I am taking as your children now.

Ok, that's right.

I am talking about cousins, aunties, sisters etc.

No no no. No cousins, no sisters

Including the time you have already spent here, how long do you intend to stay in the UK?

Ahh, this a very difficult question to answer. Because eeh, I really need to, am not, that one I have not decided yet. I have not decided yet. I feel like I should do something about it. But because I have stayed here so long, I find, I have been going to Africa, about four times during that period but I just find I have lost touch with the, with the system completely. To go and stay there it's like I am stranger again. To start all over again.

When you say you have lost touch what do you mean?

I just don't fit in, I don't fit in with the way the lifestyle there is. I just don't fit in. And we also might say that if I were to get ehh, if I were to go there and get a job which is look like it can be stable, probably I could go. But I don't really think so because

of the children issue. I feel am, am am stuck here for a while. You will also realise that the children who are born in this country, even though you try to educate them quite about African situation, or even if you take them back to Africa you show them the place and things like that, they still think that this is their country. And to the extent that, sometimes we even feel that they will not go back, am just facing the truth. Yaa. Ya, the way they talk! Even the ones who have moved out and gone to their own places. Who are working after the university. They don't, you just see that their focus is just around here. Even if you talk about, ohh, you know our house in Africa, if anything happens, what are you going to do with it? Are you going to, they don't seem to be caring about any houses in Africa which you have or not.

And how does that make You feel as an immigrant man who still has attachments that side.

Oh, ya! Well, being being, from my cultural point of view. From my culture where I come from, it is a really disappointing thing. Because it makes me feel just that I am lost. Because according to my culture and being first born in my very big family, people expect a lot from me. To the extent that it forced even me to go to the village to build a home. Even build a, I am still building a very big house there, which am not even living in it. But the reason, I just have to do it. It is like am doing things for other people. Am not really doing it for me. But am just expecting that at one time when am old, towards, nearly towards the end. When all the children have left the house. This is now, I am coming back to the question u asked me. When the children have now left the house. I probably will now have time and go and stay there. That's when I think I will may be go there. But the question is, go there with what? So there is need to develop some economic base. Or some economic income. Either from here or from there which can make me to stay there. The children are expecting me to go there anyway. They keep saying, but dad, when we are all gone you are going to preach the gospel in Africa. You and mummy are going to stay in Africa, back home?

Why would they saying you are going to preach?

Yea because eeeh, once in a while, I like the idea, I like the idea of, I like the idea, I like..like theeee, they know that I like God and things like that. Even though I drink, but they know I like that. So they just think that. I don't even know how they think like that. It is a very strange sort of, because I never told them that. But they just think like that. Sometimes may be because I invite Christians in the house. So may be they have the idea that I am going to be influenced to that direction. Ya.

And does that worry you that thats how they view you.

It doesn't worry me because sometimes I think it is a prophecy, which I must take very seriously (*laughter*).

How would you describe your health in general? Please describe to me your health in general.

My health is not good. I wouldn't describe my health as good. Because, first of all I have a drink problem, which I must confess. Secondly, the effect of HIV has its own, eeeh, incidental effect on my life. Because it causes depression. Well, long before, when I was diagnosed, it was worse because at that time, I couldn't accept it easily. But with time now, it has become as normal to me, because it is as if, as if it is not any big deal. Because am just a live. But theeee, the thee, thee, side effects of medication sometimes is not very pleasant. And also the worry, eehh particularly the issues of adherence. Because if you drink sometimes, you forget to take

medications. If you forget to take medications, I have now changed medications so many times.

Why is that so?

Because of adherence. And you see as you keep changing like that, it becomes very worrying. So my health is not that very good. No, I wouldn't describe it as good. Especially on the mental side. I worry too much about this or that.

And do you seek any support in that area?

Well, I seek support. But just like adherence. The support you get, you get it. Intellectually I will accept it, but practically I may not be... taking it. You see intellectually, somebody is telling you and you see you appreciate that it is good, you can see the sense and the logic, *cough*, but to follow the steps, for example I did a course which is called expert patients programme. In which they are telling you how to identify your problems, make out plans. Do these kinds of things. How to sort it out so that you can be able to, to create a programme, you know, monitor and evaluate and things like that. But then to to, to adhere to that kind of regimen becomes again difficult. Because ok, I know that I wanted to do this. May be do some exercises. Or do something. My plan this week is that, ok

I will just drink about two beers this week or something like that. Those plan, disorganisation! Is what I can say that is in play. But again depression comes in. And depression also comes in not only because of myself alone but also because of these, am also living with a family. And then also, you you I can also not take my, I can't subtract my life away from them, so am forced not to be free to be do what I want to do. Because I must also try myself to be. Sometimes you have to separate with your wife for a year. Because of the question you can't cope because of this and that. And then when again you go down to, to to be away from her, life becomes so difficult you get depressed. The children are also,

Do you have to separate because of the situation you are in or it is just wanting to take a break? When you say you go away for a while, is that forced on you or

It is it is, at the time you are separating you are not thinking that you are coming back. You separate thinking that it is forever, but as soon as you go. Yea, the the. As soon as you go and you are there, then you feel you are missing. And I believe the reason why you are coming is because the other party also feel they are missing too, that's why the, that's why the thing comes back. And particularly children play a very big role in it. Because when the children start talking about daddy is not here, common! And things like that. The the theeee, the children become like a ball game. So that when the children are involved in it, then u find that u, me and the Mrs. we, we sort of find that we just must stay together. Because the children are may be the children are complaining. She see the children looking gloomy or may be a little bit worry about daddy is not here. Or when I pretend that I go to visit to see the children when now we saying good bye, that oh I will see you next weekend! You see that the mood is changing as if somebody is dying. You know what I mean? Even you, even even me myself the man, I feel like crying, I am leaving my children! You know what I mean? Things like that, they play psychological impact on the question.

And is this something you experience quite a few times?

Yea quite a few times.

Over the years?

Yes over the years? Yea. Quiet few times. So I wouldn't say it is a stable relationship where by it is stable, but I would say that it has always just straight forward one good

thing. But I would say, that it is better than the majority of the people I know. Because majority of my friends I know, they have left each other forever. Because at least me myself, even with that alcohol problem, but I have at least I have maintained thee, ya, because I at least I sacrifice. I do not, I do not, sometimes if the woman becomes aggressive or things like that, I do not impose my male thinking so much. Or to say that now I must I must make things so hard for her. I just give in to whatever, and it works,

And does your condition, you said that you have drinking issue, but does HIV play a role in some of the separations?

No, I don't think HIV play a role, especially in my case. It doesn't eeh because when I was first diagnosed, it was an issue. But as am already diagnosed and she is taking medication and I am taking medication as well. So the issue of HIV is not now creating a problem because we are not discordant partners. We are (concordant) we are all, yea we are having HIV. And so the HIV is as if it is not there. But, the HIV has also played a cohesive role. I mean it has also created cohesion between us.

How is that so?

Yea, because eh, when she was diagnosed with HIV and am also diagnosed with HIV. It is like we sort of found that we are now, we can only live together. It is like she expected that I was not going to be too much of a player, ehe?...and I was also expecting that she was not going to be too much of a player. This is not theoretical, it worked in my case. And eeh...so it went like that. But at the beginning there was a big trouble.

So you were diagnosed while in this current relationship?

Yes, but you see, the thee, I can describe it this way, she was giving me this trouble on and off on and off. So I went to ..., but I was not living with her at the time when I went to ... I was separate, during that year also I was separated from her. So I went to ... too, went to ..., when I reached ... my parents knew I was not living with her. And you know the ... people, especially the big men there and mothers. They bring me this woman after this woman after this woman, saying that you have to marry now (*taping the table to indicate the emphasis*). So, when I went to ..., I ended up marrying another lady. But when I married this lady, she (*lady in England, current wife*) knew obviously that I married another lady and she was very jealous about it. But am not bringing that as the issues. Instead of even disclosing to me first, that she went to test and found that she is HIV. She is caaalling my family!, which is very strange very bad. Some people, may find it very very bad. You should have told me first. And telling my brother, the one I was telling you, that she went to hospital, checked herself, and she found that she is HIV positive. And by that time, I was still in ... I have not come back to London.

You have not tested yourself?

I have not tested I don't know! So she tells my, my brother comes and tells me. Do you know? Eeh..The lady (*lowered tone, mimicking whispers*). So I say what is it? It is not good news. I say what is not good news? She say that eee, she has been diagnosed HIV positive. So I can assure you! IF YOU GO BACK TO LONDON, DONT SLEEP WITH THIS GIRL AGAIN! So you can see the attitude of people towards HIV (*participant's comments*). The brother thinks that she is the one who is having it, I am not having it (*laughs*). So you see and do you know at this time, there is a lady who I married just in the house. I have just married a girl you see, she is in the house, we are in Nairobi and the lady is just in the house. And he is giving me

this information now. So when I come to London, I didn't come with the lady here. I left her there for a while. Am coming am coming am coming am coming "dddddddddd". Well, do you know the truth? The truth is that all along, I was suspecting that I am HIV positive. I was meeting friends who had been tested positive. And I was suspecting that I was also positive. But it did not occur to me that I should also test myself. An in fact my opinion was that, testing myself was a very silly thing. I'd rather just, when am positive, after all if am positive I will be positive. So why should I know and worry. Let me just be happy now, eeh?

And what made you suspect yourself?

Not clear. Was little bit having several other, extra, outside. I was having other ladies outside. So I was just suspecting that may be. Yea, I was suspecting but obviously I had not tested. Now when I come to London, I just started quarrelling this lady. Because when I came to London I did not go straight to my house where I was living before I left to I came to her. And I stayed with her I ask her. Because I was trying to console her a little bit. But at the same. Because also there is also allocation of blame here. Because she is, she doesn't seem to be, so much concern by blaming me that may be it is me who brought it, which I found unexpected. Because I was expecting that she was going to have a go at me. That am the one who made her, brought it to the house. But when I when I, it took me time. I asked her are you damn? What, were you sick? That no. So why did you go to the hospital? Because her friends have been tested positive positive. I knew she had a peer influence. The friends had been tested tested. Were already taking those new medications which started those days. The DDIs and those ones which were, so she just went to test herself! Eeh? She just walked to the hospital and tested herself! Without being sick! So I found it really something very strange. I asked her why did you test yourself? We had a very big quarrel about that. Why did u go to the hospital and just go!? On the other hand I said, ok now you have tested yourself. I see her taking medications, I see her really really sad. So the house is always very sad. We had a son there, the son was already old now. Feeding the child there, (*murmurs not clear*), I just said my God! It took me a while before I tested. But when I went to test, I did not shock me because I tested knowing very well that I will be positive. So I better just test and I also start taking these medication. So eventually I tested. And found myself positive. Then, let me come now to the point. Then we joined up together. So that separation which was there before I went to ..., got lost. We became now newly freshly together. Now my worry was how to get rid of that lady from ... The one I had just married. Because I was now thinking, supposing I just took somebody's daughter and just messed her up. I hope she had not catch it by now! I just knew I cannot bring her to London. Because how can I bring her to London and I am positive? Eeeh, one day I was writing a letter like this to the lady in And I got drunk and I left the letter unfinished on the table. She took the letter and wrote down there (*meaning at the bottom of the letter*) that "do you know that your husband here is HIV positive?" And she posted the letter to her! Without my knowledge! The lady just wrote back to me and said, posted me back the letter. I opened it like this aahh (*showing awe*). This is very funny story. I said why did you have to tell her? So why do you want to infect her? (*wife asked back*) In other words, she just doesn't want me to marry and continue with our relationship. But at the same time, because it is not her problem, it's not her business anyway. So anyway that is how the story went. Let me not drum you so much with my stories, and you and without focusing on your.

When was this? How long ago were you diagnosed?

That was in 1998 when I was diagnosed.

And the second wife, if I may call her the second wife.

I married her the same, 98 when I was diagnosed, but the second wife I married her in 1997. November 97.

Did you follow up to find out whether she also got infected, because I assume you were involved sexually?

Yes we were involved sexually, but i did not have to follow her. She had already been told by this letter, which went to her. She wrote to me again that she now know, defiantly, telling the other lady that I already I don't care even he he is positive or something. But I think that is just a way of trying to be, funny with her but definitely she is shocked. So slowly by slowly slowly by slowly. I kept on writing to her not telling her exactly what I mean. But I was ignoring her, and then I found out that she married somebody else. Then I said, thooooo (*mother tongue to express relief*). Clapping hands as if to dust them off, I am happy now. Then I followed it up. Because when I went gain in, when I went back ten years later. That is in 2007, eh to burry my dad. She was very healthy; I said you are very healthy. She said, you are also very healthy. She told me; my daughter is now 8 years. I said ok, I am very happy now. I can see that she may be, she escaped it.

How does that make you feel?

I felt good! I am not feeling bad at all. But maybe she got positive and she accessed may be some of these medication. I do not know.

And you have never gained courage to ask her?

No, no no.

Why?

It is difficult. It is difficult u know. It is difficult to just ask to go to that area. Unless she writes to me and ask me again, you know now am sick. Yea something like that. She was also in other relationships when I had her, when I married her. So it is not necessarily me who could have transmitted it.

And is this something you knew then or this something you knew after you read more about HIV?

Oh, the possibility that she could have been infected anywhere anyway. That one is a common knowledge. That one anybody would know that if it is an infection it can come from anybody if it is only infected by people to people. Then the more people you have, the more likely that one of them can, ya, so that one I think is a common knowledge.

You mentioned earlier on that u might have suspected. How long before that do you think or let me call it how long do u think u lived with it (meaning HIV) before it was confirmed?

I had a relationship with one lady in 1993, who I did not who I did not really think was healthy. The other ones who I had relationships are all well, they have CHILDREN AND THEY are after me. And they are all doing well. But that one in particular, I wasn't very sure. Because she looked a little bit funny. So I thought that lady in 1993, I may have contracted something from her. So that is when I think, 1993 – 1997/98, it's about 5 years. I think I was already having it.

And since u got back together, and u probably have discussed with your wife, is there any possibility that also says sometimes says that may be I suspect I had it long before

No I don't discuss. We don't discuss that. I don't...we don't go into the question about who may have brought it. Well, she has she has already been mentioning like that. You know the way women are. Sometimes when I drink, and she will quarrel about some small thing. That's why you brought for me HIV whatever whatever. But you know, she just says but I don't take her seriously and I don't pursue the issues or anything like that. Ya, because, she also is now very well versed and educated in this matter. That HIV can be transmitted in several ways not necessarily, *not clear*, because our first born son was HIV negative is HIV negative and he was given birth to by normal birth, not caesarean. So and he was breast fed. So it means that when the son was born in 1993, January 1993, that time we probably were not both infected. And it was the same 1993 later that I had a relationship with another lady that I was thinking. That means after the child was born. So maybe that's why that was another point which vindicates my thinking that I was infected in 1993. Yaa. But also God willing, when we had the young daughter in 2000, the technology had already been raised to the extent that the child is also negative. But we were both positive. Because of the fact that, this idea of caesarean and medication. We took caesarean and some medication, and the child is healthy.

And breast feeding? How did u manage the risk of.

No we did not breastfeed this one, the little one. It was just bottle.

And that was mainly from professional advice?

Teaching ya. Professional teaching.

And u said your brother was called, is there anybody else who was told about the status, because she was saying her status?

Yea, my brother after she tell my brother, they told my mother as well. Yea, and they stop there. So nobody else in the family, it became a secret. Nobody else had to know anything at all.

Up to date?

No. I don't even discuss it with my mother. Even that day when they talked to my mother like that. My mother, we talk a lot with my mother, relating....my mother never sat me down with me and say eeh! *Nyathina!* (my child) what is this? She never told me anything. We never discussed it.

Why is this so?

U see there is certain things which create either a shock or state of denial. Whereby she just denies it and puts it off. And she even thinks that if the woman already got it, my son is clean. You know it is a denial way of looking at it. So I didn't. I did not that night I didn't discuss it with my mother...the issue. It was just a secret between me and my brother at the time.

And since then? Has anybody else, has it cascaded into the family?

It has cascaded, but without me doing it. It is her who did it again. Because when she went, I went with her home, she again reinforced it to my mother and things like that. So she discusses with my mother, but not me. I don't discuss with my mother about this.

Why would she do that?

It is, I don't know how she is thinking. Their (*referring to women*) thinking is difficult you know. That brings me to another question. That is her character. She sort of like, sometimes she wants to character assassinate me or to put things in a different way, u know. But that is her character. I found out she is discussing these things with people like my mother. I know she does not discuss it with, other

members of the public. But I know she discussed with my aunty. Because that aunty also was found positive. So they are discussing together with my aunty together.

How do u know? Has word come round?

Yes yes. That my aunty I don't discuss with her that she is sick or positive. She discusses with my mrs. But when, I have not sat down with my aunty and discuss with her what kind of medication she is taking or anything like that. But they are discussing with my mrs about side effects and what she should do. Because it is like, my mrs is like an expert patient. But she is trying to...because the other one (*the aunt*) is in Africa, and during the time when she contracted the medication wasn't as much available as it is in Europe. Yea.

And how would you describe your reactions and your brother's reactions or your mother's reactions when you had this bombshell?

My brother was sorry for me in a way. But my brother was also in denial. Remember he was telling I should not go and sleep with the lady again. So according to him, although he is an intellectual he may have been hiding from me his true thinking about what I may be. So it could have just been another way of making me comfortable. But it, that was it like that.

And since then have u had an opportunity to discuss with any other family member just to find how they feel, may be now, how you are at any point. No, no I don't discuss with them at all.

Why is it that HIV is not discussed openly?

The only person who discusses this when I go with her to ..., every time she hears one of my relatives is sick. She openly tells them have you gone and tested for HIV? She goes around and quickly goes to that subject. And I keep on telling her, don't just assume everybody, *laugh*, everybody who is sick in hospital is HIV positive. Although myself, I keep telling people to be tested, but I don't know why in my own family I don't go, talking to my brothers and sister to go test themselves. I don't go round, *u know*, like an advocate or that kind. Not in my family not immediate family members.

Is it something you have decided you are not going to do?

It is just something that happens out of the subconscious. It is now that I am identifying it as something happening. I never thought about it. I never gave it a thought that now I have decided I will not discuss this. I don't know whether because, by doing that I will be implicating myself and I fear implicating myself. I do not know. May be that's the possibility, the subconscious. But I don't know the reason openly. Ya.

That's interesting because you interact with them, I suppose you call them, you go home you are together, but that area, even with this brother who was told since the it has never been discussed again?.

No no, we don't discuss it again. But only with the same person who told him. Because he came to visit me here, and he said that he discussed with my mrs. That you look very healthy and no one can even know that u are sick. He discusses with my Mrs., but he don't discuss with me. He don't create, unveil that subject.

Is it because of your position in the family? U mentioned that you are first born.

Yea. Or maybe he thinks that by discussing it he will be opening a can of worms because he doesn't know my attitude towards toward that that sort of status. But he does know that I am HIV positive. He knows that I am HIV positive but I didn't tell him. I myself didn't tell him that I am HIV positive but he knows that I am HIV positive.

And your mum, because she has also been told. Has that affected the relationship between you in any way at all?

No, it has not. It has not shown any difference in terms of whether, Yea, to some extent I see things happening, but it's not directly.

What kind of things?

The kind of things are a little bit difficult because this is my imagination. Because sometimes when I send money to do certain things, she end, up eating the money or things like that. And am just suspecting....is she thinking that am going to die soon or what. That is just a question mark. But I don't think that is the issue really.

Are there any of your family members also living with diagnosed HIV? Apart from you wife, are there any members of your wider family living with HIV?

Yea, so many have died. My uncles have died with HIV. So many have died with. Nearly the whole village have died with HIV. And when I first went home for the first time in 1997, the time when I was going to marry this person this second woman. I was very skinny. Extraordinary skinny. Whereby people when they come to see me. They were thinking that they are coming to see a person who has lived in London for many years, a big man! They saw, they just get shocked. I see that they are getting shocked, in their head.

How do you deal with that?

No no no. I just I just just don't care. In their head they are thinking. Like one my uncles came and saw me and I was just having a hangover. So he came and asked me, oh! You don't look very well. Koyo omaki koso no ango? (*u feel cold or what? An expression used to ask if one is ill*). You know, in my brain I think I know what he is asking me. They won't ask you that you are HIV positive. But you can see their imagination because they know that disease they way it is killing people and they know the stages that people go. So when I was there, they even thought that I was HIV positive before I got the information that I was HIV positive. But when I went the second time, because I had taken medication, and I was eating well. They saw the changes, everybody is shocked. What is this? This man again. Uncles are coming, eeh *dendi ber! dendi ber! Denda ber? kara denda berni kara denda ne rach? Hearty laughter, (your body is good your body is good, my body is good? was my body bad?)*. In other words they thought that I was, HIV positive and I was soon dying. But when I went back, they saw a completely different, opposite, ya. And at that time also, medication had just started around 1996. And it was not very much developed in around 1997/98. The combination therapy had just started during that time. It had not reached Africa by then. So in Africa when you reach the stage of at the skinniness as I was (*ka ngato ne odhero kamano*, when someone was skinny like that), you knew that he was going to die. And they could not see how I changed to be this way. So it was eeh. A little bit ya, *Ka koro ka mamau (if even you step mum)* let me tell you, if even your own, my younger mother who is a Christian, they call me privately and tell me to kneel down they should pray for me. Not that when people, they say that not when people are lying down in hospital dying that's when we are calling people to pray for you. I said no no no no, you see they talk to you like that. What I think in retrospect, were they referring to thing that they thought I was going to die? It was a really being skinny. But to me I was attributing it to: living alone, in London. Drinking too much and not eating. Because living alone drinking too much and I am lazy to cook or something like that, so I attributed it to diet. I dint attribute it to anything to do with HIV.

So when during this time some people want to pray for you, you see shocked faces, what goes through your mind? As much as you are strong outside.

At that times I was not yet, I did not that I was HIV positive. So it did not matter to me what they were thinking. But am now looking at it in retrospect, and seeing exactly what was going on. Because at that time I was just me. And it was just me a person living alone and drinking too much and not eating. That was me at that time. So whatever they were looking, they were looking at someone who was not taking care of themselves. I was not seeing that they were looking at someone who is HIV positive. Because I had not tested.

Untill the phone call came?

Until the phone call came, then I knew. Yea.

Did u stay long for the phone call?

The phone call came when I was going to the airport, the same day. And I was very sick at the time. Hmm.

Could you please describe how your life and those of family members have been affected by your/their HIV-positive diagnosis?

Yea. The, eeh, those around me, thee since I was diagnosed the beginning was bad. But I must say that being in England, the support groups like Body and Soul and even places like this (*referring to venue*) there were various support groups. There were several therapies that were going on like massage and things like that. And also the medication and the nurses and the advice and things like that. Really helped to encourage. Because especially if you go to a support group, and you see the hall is full up of everybody who is HIV positive. Everybody is telling you their problem when they were very sick. And now they are, because of medication they, you see it changes your thinking about the HIV. It did change my thinking about the HIV like that. And with time, I just realised that it was part of me. And so I don't think about it anymore. I don't think about HIV anymore, as in it is in me no. I only know that there are some pills here that I take. Yea, but I don't think about the HIV. I only think about either I feel depressed or I feel lethargy on my left leg. Or this medication is causing it, they remove it again, replace with another one and things like that. Instead, it is a subject which I have taken to learn about. Just to learn about what it is, what you know. Because I am also now at the health centre as the community health champion and also health trainer. And so these kind of courses in sexual health and things like that I have been participating in so many of them. So I know exactly what is going on. In the development of the medications, what type of medications are available. The ones which I have taken, the ones which are remaining for me to take. If need be. But I don't want to take them, because if this one is still working then I better not however hard it is take. Because like for example I am on the regime where I take some in the morning and some in the evening. But the doctors are always advising me; why don't you just take this one which you take once a day. If taking in the morning and evening is becoming difficult for you, and you can't not adhere because may be in the evening after you have a drink you forget, why don't change this one, and just take this one which you take only one per day. So that u don't miss every day in the morning once u take it u finish the day. But I refuse! The reason why I refuse is that if this one is still working, why I don't leave that one for the day when this one is not working.

Pause for the phone call

This brings me to another thing. People like my sister when I brought her to London and she knew that I was HIV positive.

Who told her?

Because she knew already because now, everybody, my family they now knew, the brother knew, she knew, my mother knew, I don't know whether they are other people they knew but I don't know. Or may she knew, I don't know at what point they knew.

How do you confirm when they know, or how do you suspect that so and so knew?

I knew that she knows because when she came in, she came to live with me. And this parrot here (*this my wife here*), she can't stop without telling people that eeh that there is HIV disease and things like that. So she knew when she visited. May be she did not when she was coming to London in 1994. But then, when she came in, when my, when my Mrs. She open the toilet, when they find her, she putting a lot of tissues on the, *a very hearty laugh*, on the toilet. These are issues. They may not tell you to your face. But they also scared, even living with you. And I can't I can't say that it is eeh, it is something that happens. Because me long time ago when people were HIV positive, like the friends of my wife when we visit them, even sometimes am scared of taking the same glass. Just because I think that you might catch. These issues which I have lived with myself even before, even may be that time when am fearing like that already I have it. You see? Only that it has not been confirmed. So these kind of questions about stigma is there and is very serious. And especially among, eeh. Let me tell you one thing what I found out, in my lifetime as an HIV positive person. Very many people who are not diagnosed HIV positive, are so ignorant about HIV to the extent, where first of all they think that you are going to die. Even up to today, even up to today! The idea of saying HIV or AIDS, they think you are going to die. They don't know that people can now live and take medication. That one, is that something you find even with people in England as well? In England yea, yea, even with people in England here, they don't know anything about it. People don't want to know anything about, anything, mostly sexual health and especially HIV. They don't want to know, especially Africans in general you know, discussing about sex is just out of the question. ya, *phone*.

At the beginning you said that when you were first diagnosed, health life was very bad. Do you want to?

Hmmm. First of all depression. Secondly, the side effects of medication at that time was so horrendous. Like DDI was a big tablet like that (*illustrating the size of tablet*). And as soon as you take it like this, the nausea that you feel! Sometimes some of the medication if you go to the toilet, you pees blood.

As a side effect?

As a side effect. And sometimes, there were regiments whereby either you had to eat it either one hour after food and one hour before the food. And when you go out, your life is completely disorganised. So, which, you don't know what time food you are going to eat. When you go out time you have to take this one. This one you must take with food, they are combinations. This one you must take with food. So you want to take it but if there is no food? You see if there is no food, you don't have food at that time. So the life was completely disorganised. And then, comes the issues of, that depressed state. Comes the issues, at that time, the issue of even jobs. You want to go to work, you have to take this medication. You have to do this. It was completely confusing. Leave alone the side effects alone, there was no clear cut knowledge about, that this thing (HIV) is going to be controlled. It was that if we are lucky! So the idea rolling in your head that, this thing is going, the idea, people

who are people started achieving undetectable levels at a very late stage. Because the virus was oscillating from millions to thousands millions to thousands. It was not something like that. So during the days when the undetectable levels came, people now started feeling a little bit confident. But the depression which was coming with it, that made it even worse. So you don't know how to handle yourself. You look at your children young like this, sometimes you just shake your head. Because you don't know who is going to look after them. It is even worse if you have the children, because you just don't know how to plan. So I die they are going to be taken to the orphanage or something like that.

And have u have gotten to telling the children? May be the bigger one? Any of them know there is HIV in the family?

Yes yes. The bigger one knows there is HIV in the family. But the mother is the one who told him. Again it is the mother who does all the speaking. Yea. I have not sat with my son and told him that I am HIV positive. But the mother had told, has told him.

And how does that affect the dynamics in the family? Has it affected the dynamics in the family?

They do not even see, you see they have been told at a certain stage. The bigger ones now, the ones who have already left home, they reached a stage when now they realised what it is. But because they see us as just normal, it doesn't impact on them that it is something really serious. I have never seen them really, going like they are a little bit sad because there is what what, no. And even sometimes when we used to go with them to a place called the Body and Soul, they take themselves that we are going to, not clear, party and they are just busy playing and enjoying themselves with the other children. It is like a normal day to them. Yea, I never saw them a little bit sad or I don't know whether, they did not even understand what this HIV is about. Because you see even in the media in this country, there is very little about HIV in the TV. It is not much. You see. I remember attending a meeting in which they were saying there should be a little bit of, eeh, a little bit of publication of certain things even in the media, so that the young teens should even know what is outside there and should be able to protect themselves. Very little is in the media. So, I can't say they saw, may be in the school, may be somewhere they will hear something, may be someone is having AIDS, somebody is having what? And when you told your daughter or your son that you are having AIDS or HIV, they don't know much the difference between that HIV and AIDS. Because you are not going to tell your child that I have AIDS and you know very well that u really don't have AIDS. You just say HIV. They don't know what HIV positive means and what AIDS mean. Unless you are sick in the hospital, that's my opinion, unless am sick in the hospital, then I tell them my son or my daughter that I have HIV or AIDS. I think that is when it will make an impact. Because when they just seeing you normal, just doing things as you always, they don't see much difference. But at the beginning, they could see a little bit. I think they could see but they wouldn't, they would just say are you sick? But sickness could just mean normal sickness.

As a parent living with HIV, do you sometimes compelled to may be try and talk to your bigger children about.

Oh, yes. I have spoken about sexual health. I have spoken to them about sexual health. But I have rarely specifically touched on HIV itself. Just sexual health, STIs and the need to protect themselves. Sometimes we even joke. When we are going to some of these support groups, we normally distribute condoms. And I will make

a joke with my son; how is your girlfriend man? Have that (meaning giving him a condom). It's just an, because also as an African, it is not easy for an African man to just discuss sex with their and especially even if it your son. More so, if it is a man to your daughter. It is even even, that is even out of question. That is even out of question. So it has been difficult.

So in the back of your mind do you sometimes fear for them, knowing that you know so much that you can't share with them? Do you sometimes fear that they may be putting themselves at risk?

No, I am just confident that sexual education which they get in school will be enough to some extent. And there is a cultural barrier which puts me off. I just find it very difficult as if someone has tied my mouth. In fact I find it very very difficult just to discuss about sex and things with a child you know. It doesn't work out to me. And even the bigger daughter who is not mine, but who is already a grown up. To discuss sex with her and she is not my personal child. To discuss issues about sex and things like that, it just doesn't work out for me, laugh,

And do you think your wife does a bit of that?

Yes she does. She does it a lot.

To all of them boys and girls?

She sometimes does it even when I am there even I hear her talking to them. The children's reaction is always laughing giggling you know what I mean? It is as if it is not a serious matter. But they are getting the information which is going on in there.

So is there some problem with gender in talking about these issues, is there some gender issues?

Yes there is some gender issues. There is some gender issues because it is easier for me to talk to the boys. For example, I had a son, I have a son who is nearly the same age as my son, but he is not my son. And then I have a daughter, who is older. These are the three who have left home. But I will sit down with them, maybe I have had a little drink. And they are discussing about their girlfriends. And I joke with them about their girlfriends. And I talk to them about homosexuality, things like that. They joke me with me, oh that one is gay, *murmurs*, you know what what. So I talk, with them, I pretend as if I am making a joke, you know what I mean? But I know I am talking with them about something.

Is that intentional?

Yes it is intentional. Using the jokes and they laugh and they say look at that bla bla, they laugh laugh. You know what I mean. So it is like that they are now ready to talk to me about their girlfriends, what what what what what, seated. So you know, you use the jokes like that to do it. But on a sober mind, I can't just sit down with.... them and start talking about; do you know today, there is something I want to talk to you about. Be careful about diseases and things like that. When I drink a little I would say it. I would say it in passing, things like that. And they would be talking to me about their girlfriends. But they wouldn't talk, one would talk about the other person's girlfriend and this person is talking about the other person's girlfriend. Not that daddy my girlfriend you know, directly. So one is abusing the other one; oh common you your girlfriend is like this like this you know what I mean? So in the process you know what they are doing. Because direct like a monologue, like a dialogue is simply not easy? And I think there is some cultural issue related to it.

And how about managing the risk of disclosure to them through things like medication. How do you deal with that? Because they are big people now they

go they see oh daddy is taking this kind of medication and mummy is taking that.

They know that I am taking medication and they know it is for HIV. Yea, they see it all the time. They see it everywhere because in the house, we don't hide medication. Or go and get for me my medication it is on the table the other side. And they know that we are taking medication, several medications and it is for HIV.

It is just it is not discussed?

It is not discussed.

What do you think are the main issues for you as a man living with diagnosed HIV? African man living with HIV. What are some of the main issues that HIV specifically brings to you as a family man?

Eehhh, the issues that it brings is that it brings, well as a family man, it brings the issues of fidelity. That is between me and the mrs. Fidelity is an issue, it is important here in this case. Yea because, my mrs is now conscientious that I am conscientious person and that I will not deliberately and I will not go and have sex with another, without, knowing very well that I am also HIV positive. I also trust her, even I trust her even without HIV. So it is not, is a question, question of fidelity is one issues. Yea, the issue as an African man is, as we have already spoken about the issue of teaching the children. That is also an issue. But then the issue is that the teaching is not direct. It is indirect. But it is there. It is there but it is not directly but it is indirect. But as an African man, I don't see anything which specifically depicts an African man different from any other person. Yea. I don't see many, I don't see much issues there to be honest.

What do you think are the main issues for your family members arising from your/their HIV-positive diagnosis? And are there issues that you things the family faces. Apart from you, are there issues that you think the family faces as a result of HIV within the family?

Within the family, Eehh, no.

For example your wife, your children, relatives? Are there issues.

That are facing the family as a result of HIV being there? Not that I can, not that I can see in particular. But I would think that HIV brings in something that makes the family unique in itself. Yea.

In what way?

Unique in itself in the sense that if both mother and father are positive, there is some sort of cohesive relationship there, yea, which comes in as a result of the uniformity of their status. Ehh, there are also other ideas, but when it comes to the children, to my case in my case, I have not seen a big difference between whether if we had HIV or if we did not have HIV, it could have made a difference because the children would have been different because of the HIV. Because as far as my family is concerned, the children are so much detached from this issue of the HIV. Because they know that we have HIV they know that we are taking the medication. But they don't seem to be part of it. They are just like other normal children. Yes, also one thing which I think is serious issues, only if, other families or other friends outside were to know! That we are HIV, then it would affect our children seriously. So the idea is that if it is just between the nuclear family here, our children may know it but they wouldn't go and tell anybody that you know my mum and my dad, they are HIV. No, but if any of the friends were to know that, then it really affect the children. Because they will have this stigma that oh, people are saying that my parents are like this like that.

So how does your family deal with that then? You don't discuss it, but at the same time you don't disclose it. Who writes the rules?

As a family, we don't disclose it. Yea, it is just a normal rule. It is a, the rule is efficacious by itself, because everybody fear for themselves. Yea. The children fear for themselves. They are protective of the parents' status. They wouldn't want anybody to know that this is happening in the family. Yea, people, friends come to visit all the time. But the friends have no clue that the parents are, either HIV positive or not. Except for those parents, even other children of other parents who know, who are HIV positive. When they come to the house, they doesn't seem to be bothered by the, as far as I can see. Unless their parents also told them, yea. That do you know that that family they are also HIV positive, which I do not know.

You know, it now brings us to this question. Sometimes we discuss about other families, about their medication and things like that. But what happens naturally in my house is that we switch over to Swahili. Yea, we don't do it deliberately but it just comes naturally. Unajua huyu mwanamke alikuwa anasema hivi na hivi na hivi. Yea, alikuwa anachukua hi..eeh...anadanganya ati hivi na hivi. We switch off!

Why would you switch to Swahili?

I....I don't know?it just happens.

Is this only when you are talking about these other families also living with HIV?

Yea, we just switch off when the children are there.

Oooh, they don't understand Swahili?

They don't understand Swahili. So we switch off when they are around. When we are talking about somebody else about HIV, we switch off. Even the word HIV we don't use in the house.

You use what? Ukimwi (Swahili word for HIV)?

Ukimwi yea, hii ugonjwa (this disease). Yea. So we don't use the word HIV when they are in the house. We know that the children know, but we don't go round using the word HIV or something like that. And also at the same time also, even literature. Like these magazines like Positive Nation and things like that, we don't leave in the sitting room anyhow. Yea. There is nobody who has put those rules. It is just natural that if I come with those kind of things, I read somewhere in my bedroom somewhere. But I don't put them hanging around on the table.

This is for friends and visitors who come in or?

No no, even for the children. So they don't read, keep on reading things like that. I don't know whether we are protecting our status from the children or something like that. The children know, only know theoretically. They also know that we take medication.

That is interesting. They know but they don't know at the same time? Yea, but we don't just like make it so obvious. We sort of hide a little bit.

What is your worry about flooding them with?

With these? No, I don't know. You know majority of these things they happen. Only now that you are asking, can I identify them. Yea, they are things which happen. But they just happen, without one knowing without thinking. You just don't want the children to see this u don't want the children to see that. That's it.

Q2. I am also interested in knowing your views about HIV-related health and social care in London.

What HIV-related services, if any, do you and your family members use? Talking about services, you said you have accessed support groups.

Counselling and things like that, what other services do you and your wife use, related to your HIV?

I would say support groups. There is support groups, there is also, some eehh therapies. Eeeeh alternative therapies, eeh like may be sometimes massage sometimes what. Which these days have become very scarce because they are cutting down on spending. So majority of the times we don't have these kinds of things like we used to have them before. Aaahh, apart from the, eeh, this one, you already said apart from what?

Apart from counselling and eehhh

these kind of things. Counselling from the either from the hospital sometimes. Depending on maybe sometimes you want to change medication and you want to think about. And these therapies, that is all. These kind of things. Because these days again we don't access much of these things. Because once the medication is going on, all you do is to regularly go to the hospital and check blood tests. And if the blood is showing that you are still undetectable, you just continue taking your medication. It has become something which is just check blood every three months. And then so long as everything is alright, you just continue with taking your medication and you just continue with your life.

How far do you think that your needs and those of your family members are met by HIV-related services in London? Do you think services meet the needs of you as a family with HIV and other families in your position?

Yea it does, but I don't think it meets the needs of the newly diagnosed. Because the newly diagnosed, need to have a lot services available to them, which during my time when I was diagnosed, these services were available. But these days they are not. For example these days, they are not available to the extent that it used to be. For example buddying, whereby a friend would go to another friend and they just discuss about how do you feel today and things like that. They used to be there things like that. These days they are all gone due to lack of funding. And the newly diagnosed person is a person who needs a lot of support. He really needs a lot of talking!, every now and then!. So that they know that people are living other people are also living with this thing and it is not a life and death matter. It is something that can be managed. Because those newly diagnosed, even right now if someone is newly diagnosed. He just feels the same shock. Because he doesn't know the development. It could be that he has been reading these things or she has been reading these things intellectually. But whilst they are diagnosed, they will need it becomes another matter altogether. But because you have been living with it, you have been taking medication, you have known that you can live with, it becomes a different matter altogether as well.

In your view, what should be done to improve HIV-related services to meet the needs of individuals and families in similar situation to yours? How do you think services could be improved? Both clinical and social, what could be done? On the clinical side, I cannot say much on the clinical side. On the clinical side, I just think that, access to medication, counselling advice, should be, should, access to medication, which I think is still a problem to this day. But then, I think that more funding to organisations, like support groups should be available so that they can be able provide some of these services.

And talking about health effects of HIV, how has it affected your sexual life?

Oh that one is a very interesting one because it has done it has really cooled me down. Yea, I have sort of, what we call zero grazing or something like that. In other

words you just stick back home. And it becomes difficult to even try to have relationship with somebody else, who you don't know their status. And because of the legal issues also surrounding it now these days, you have to declare to the partner that you are HIV positive and things like that. And sometimes declaring is not the difficult thing, sometimes it is not just the legal consequences. It is even sometimes difficult to do it because it is embarrassing in the first place also. Because it is something is carrying a stigma, to tell someone that you are HIV positive or something like that. I am not talking about myself but I am talking in general. Yea. So it has really caused a lot of eeh eeh disruption. But at the same time, eeh, it has also organised me to some extent.

How?

It is organising because that is one advantage it is organising because now that you are HIV positive, you don't just go wild and do things and imagining that this is going to be like this and this is going to be like this. A little bit more planning comes in.

How about within the two of you, are there any issues when you get involved sexually, are there any fears?

The issue is only one that even they tell us that we should not use condoms, still in a relationship, you just find yourself not using it. But they even say that even in a relationship whereby married people are concerned you still should use condoms. But the idea is that we don't use. Yea, we don't use. And the problem is that it causes a bit of a problem because my mrs takes different type of medication, I take a different type of medication. And the HIV itself have got different strains of HIV. May be she has got different strain of HIV may be I have got different strain of HIV. And therefore we can co-infect each other. These are issues which are there. Yea because, may be the strain she have can or the strain I have which she does not have I may again give her, which the medication she is taking is not treating it. Because you know they test your blood before they find out which medication to give you? So these are issues which, these are risks which we are just taking. Yea, we are just taking these risks. We know that there is a possibility of co-infection but still just take the risk. Yea.....It is another way..... It is just like before when we were not yet diagnosed. You just take risk and you know that there is a possibility.

And these are risks you started after the medication had started working or even before?

Even before.....well after medication started working of course.

And how does that make you feel?

Generally..generally it doesn't, generally I don't, I feel that she is my wife. I feel that she is my wife that is why I don't worry. But yet I know intellectually that there is a possibility of co-infection here. And then it can create a lot of difficulty in the medication. Yea, but that is the only issue I can think of in terms of making love or something like that. Yea.

Because the other issue you had mentioned about having a child. And the two of you have already used modern technology to get a child. Yea, hmm, yea.

Is there anything else you would like to add or talk about?

No. No no. I would not say much about how it affects families living here because I do not have a general overview of other African families living with HIV. But I have seen other families who are friends to us, it doesn't seem as if they have any big problem. But those families, I know that they both have HIV. They, those two, the parents, the mother and the father, they both have HIV. But I have seen other

families who have separated. They have separated because of the HIV. Where one discovers that one has HIV, and one run away. So those ones I have seen them like that as well.

Thank you. I think I don't have any other question.

Thank you very much.

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