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**Information and HIV/AIDS: an ethnographic
study of information behaviour**

By

Robinah Kalemeera Namuleme

A thesis submitted in fulfilment of the requirements

for the degree of

Doctor of Philosophy in Information Studies

at the Information School,

University of Sheffield, UK.

March 2013

Abstract

This study investigated the information behaviour of people infected with, or affected by HIV/AIDS (PI/A HIV/AIDS). It sought to generate in-depth knowledge of the real world 'lived information experiences' of PI/A HIV/AIDS, with the aim of informing information management practice, strategy and policy to better contribute to the fight against HIV/AIDS.

Ethnography was selected as the methodological approach since it is particularly well suited to unearthing complex phenomena, in marginalised social settings, among hard to reach populations. It has the potential to uncover what might otherwise remain hidden aspects of social experience particularly in settings characterized by stigma and discrimination. The sample studied consisted of 40 PI/A HIV/AIDS in the UK, recruited at an HIV support centre where the researcher worked as a part-time volunteer. It included a range of age groups, disease stages, sexual orientations, and educational and ethnic backgrounds. The interviews were analysed using Spradley's Domain Analysis.

The research has contributed to knowledge by revealing a number of distinctive information behaviours, including not only information seeking and sharing, but also covert and hysterical information seeking, destroying and hiding information, which appeared to be strategies for coping with a range of internal and external factors: reactions to diagnosis, stigma, and the need to educate and inform both self and others. The research has highlighted the complex and dynamic shifting nature of HIV/AIDS-related information behaviour of PI/A HIV/AIDS.

A model which attempts to describe patterns of HIV/AIDS-related information behaviour and explains why such patterns could develop in the HIV/AIDS-related information context has been developed based on the lived information experiences of PI/ A HIV/AIDS. The model moves beyond relatively reductionist and simplistic representations of information behaviour by addressing finer details of the complexities of

human information behaviour, particularly in life-threatening and stigmatising health-related information interactions. This could potentially illuminate ways in which information services could be responsive to the needs of PI/A HIV/AIDS, and provide a basis for proposing recommendations for information management in health contexts. Thus, in addition to paying attention to how and when people relate to information, the model has generated rich insights about complexities, subtleties, challenges and dilemmas experienced by people faced by the life-threatening and stigmatising condition such as HIV/AIDS. In addition to identifying information behaviours within the HIV/AIDS context, the model has drawn our attention to forms of information seeking which have received only scant attention in the library and information science research literature, such as covert and hysterical information seeking.

The model draws on theoretical propositions from Stress Appraisal and Coping Theory and Stigma Management Theory to explain HIV/AIDS-related information behaviours. The model acknowledges the role of emotional as well as rational factors in determining information behaviour. Recommendations are made relating to the need for information professionals and information service designers to understand information users at deeper levels if their information services and products are to contribute to the prevention and management of HIV/AIDS.

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List of abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
ARVs	Antiretroviral Drugs
ART	Antiretroviral Therapy
ELIS	Everyday Life Information Seeking
H4 hub	Homosexuals, Heroin users, Haemophiliacs and Haitian
HBM	Health Behaviour Model
HCPs	Healthcare Professionals
HIB	Health Information Behaviour
HISB	Health Information Seeking Behaviour
HIV	Human Immunodeficiency Virus
IB	Information Behaviour
ISIC	Information Seeking in Context
ISP	Information Seeking Process
KKK	Ku Klux Klan
LGBT	Lesbian, Gay, Bisexual and Transgender
LIS	Library and Information Science
MSM	Men Who Have Sex with Men
MDGs	Millennium Development Goals
PHSE	Personal, Social and Health Education
PLWA	People Living with HIV/AIDS
PI/A HIV/AIDS	Persons Infected with, or Affected by, HIV/AIDS
PrEP	Pre-Exposure Prophylaxis
SchHARR	School of Health and Related Research
STI	Sexually Transmitted Infections
SCT	Social Cognitive Theory
THT	Terrence Higgins Trust
TRA	Theory of Reasoned Action
TPB	Theory of Planned Behaviour
TRB	Theory of Reasoned Behaviour
TTM	TransTheoretical Model
UNICEF	United Nations Children's Educational Fund
WHO	World Health Organisation

List of author's publications

Namuleme, R. & Ford, N. (2011). "HIV/AIDS related health information behaviour: an ethnographic study ". In Williams, D. (ed): Conference Abstracts of the 3rd international i3 conference on the use and impact of information. 20-23 June, Aberdeen, UK: Robert Gordon University: 80.

Namuleme, R., Ford, N. & Bath, P. A. (2011). "Information disconnects for people infected with, or affected by, HIV/AIDS". In: Bath, P. A., Mettler, T., Raptis, D. A., & Sen, B. (eds). ISHIMR: Proceedings of the Fifteenth International Symposium for Health Information Management Research. 8–9 September, 2011. Zurich: University of Zurich, 2011: 220–228. [Cited by 1]

Namuleme, R. et al. (2012). "Towards a model of HIV/AIDS information 'disconnects': an empirical study", submitted to Journal of the American Society for Information Science and Technology [Accepted for publication upon minor revision].

Acknowledgements

God the almighty:

I give thanks to God for giving me the grace and serenity to live one day at a time; enjoy one moment at a time; accept hardships as the pathway to peace; take, as He did, this sinful world as it is, not as I would have it; and trust that He will make all things right if I surrender to His Will.

My Employer

I am so thankful to my employers, Nkumba University, for contributing towards tuition fees and granting me paid study leave from September, 2008 - March, 2013.

The University of Sheffield

I am grateful to my supervisors, Professor Nigel Ford and Professor Peter Bath, for the guidance and advice that enabled me to complete this thesis.

I am grateful to the Roberts Fund Post Graduate Placement, University of Sheffield for funding the researcher project known as, 'Fighting HIV on an information front'. Part of the project resulted in the development and production of HIV/AIDS awareness fliers for persons infected with HIV and members of the general public.

I also grateful to the Education Informatics Research Group and Health Informatics Research Group for providing funding to enable the findings of the study to be disseminated at the Information: Interactions and Impact (i3) Conference held at the Department of Information Management, Aberdeen Business School, Robert Gordon University, Aberdeen, UK, on 20-23 June 2011 and the 15th International Symposium on Health Information Management Research (ISHIMR) in Zurich, Switzerland, on 8-9 September, 2011 respectively.

Special thanks are extended to the SchARR Information resources group, the administrative and computing staff in the Information School, the University Library and CICS staff, whose support and inspiration was a

great source of encouragement. Special thanks is extended to the Student Advice Service, especially Jo Holliday and Sarah Woods for respectively providing legal advice when the UKBA denied my children visas and my landlord invaded my privacy

The respondents and gatekeepers

A special thank you is extended to the men, women and a child who participated in my study. They kindly granted me access to their world and freely shared very personal, private and sensitive issues about their lived HIV/AIDS-related experiences. Their experiences not only taught me the realities of being infected with, or affected by, HIV/AIDS in the UK, but also taught me that HIV/AIDS is an infection that does not discriminate on the basis of race, colour, level of education and/or socio-economic status, whose devastating effects are more far reaching than anyone not affected by, or infected with HIV, could ever imagine.

This study was also made possible through the cordial and generous support from the staff at the HIV Support Group in the North of England (confidentiality issues prohibit me from naming the organisation). They not only allowed me access to the research setting but they also offered me a job as a part-time volunteer. Therefore I was able to immerse myself in the research setting and build rapport and trust with prospective respondents.

Family

Special thanks is extended to my family for contributing over £37,000 towards my tuition and living expenses, especially Stephen for financial, social, and moral support for the duration of the programme. To my fabulous children Pendo (13 years), Joy (12years) and Benjamin (9 years), who endured my absence for two years and eight months when I had to leave them in Uganda at the start of this course. I sincerely thank them for their continued encouragement and tolerance of my stress when they joined me for the last part of the programme. Special thanks is extended to Joy for managing and monitoring my time schedules and

ensuring that I met the set deadlines, to Pendo for preparing breakfast and ensuring that I was well fed before I set off for the day's tasks, and to Benja for praying for successful completion of the PhD to enable us to go home. To my wonderful parents and siblings, especially my Mom, Beatrice and Ambrose, for taking good care of my children for two years and eight months before they joined me. A special thank you is extended to Tony Mulinda for sacrificing the comfort of his house to move in, and take care of my home for the duration of the PhD. I am deeply grateful to my dad, Paul Lumu Esq. who taught me a strong and good work ethic that has been so vital in accomplishing this programme.

Friends

To my fabulous friends in the academia and social circles, Andrew Madden, Sahlee Bualati, Maureen Howard, Halima Egberongbe, Marcellina Chabu, Juliet Boma, Mr and Mrs Sentongo and Carterknowle Seventh-day Adventist church family, I sincerely say thank you for your inspiration, encouragement and support.

Dedication

This work is dedicated to 14 members of my family, twelve of whom succumbed to AIDS in their youthful years, and two who are living with HIV, because they are the inspiration for this undertaking.

CHAPTER 1-INTRODUCTION

1.1. Background

This thesis reports a study which investigated the information behaviour of persons infected with, or affected by HIV/AIDS (hereafter referred to as PI/A HIV/AIDS). The study was undertaken in the belief that understanding HIV/AIDS-related information behaviour from the perspective of this group of people may be able to improve the planning and development of HIV/AIDS-related information services and products.

1.1.1 Why is HIV/AIDS important?

HIV has been described as the most devastating disease that has left no country untouched (Usdin, 2003; UNAIDS, 2007). HIV is unique because of the nature of its transmission, and because its ability to mutate reduces the effectiveness of drugs that help to slow down its progression, and increases the difficulty of developing a vaccine. In addition, HIV/AIDS spreads initially through marginalised communities, such as gay men, sex workers and intravenous drug users, leading people not in such 'at risk' groups into denying that they were at risk.

Linking HIV/AIDS with sex, particularly in a world where people do not freely talk about sex and death, has resulted in an epidemic that is shrouded in taboo, silence, denial, fear and stigma. Fear of an incurable disease, association with illegal or 'forbidden' practices such as injecting drugs, sex work, multiple sexual partners, and linking HIV/AIDS to divine retribution, have resulted in stigma which hampers efforts to prevent and manage HIV/AIDS (Health Protection Agency, 2011; House of Lords Select Committee on HIV/AIDS in the United Kingdom, 2011; Usdin, 2003).

Together, these make PI/A HIV/AIDS feel ashamed, embarrassed, or guilty, and afraid of discrimination. This discourages them from seeking the help and information they need to manage the illness and protect others not yet infected. Prejudice, racism, sexism, homophobia, and class-ism were reported as key stumbling blocks in the fight against HIV/AIDS (Usdin, 2003). HIV/AIDS has not only affected people's health, but has also eroded development gains by its far reaching consequences to individuals, families, communities in the UK. The escalating morbidity and mortality that disproportionately

affects women and men during the prime years of their productive life as well as the increasing cost of HIV prevention and AIDS care and treatment services such as provision of Antiretroviral Drugs (ARVs) have imposed severe and unsustainable burden to the National Health Service. Thus the fight against HIV/AIDS requires a broad response at a cultural level, in addition to a medical response (Helman, 2001; Usdin, 2003).

HIV/AIDS was reported to be one of the greatest threats to achieving the Millennium Development Goals (MDGs) (HM Government, 2005; UNAIDS, 2007). The MDGs were agreed at the United Nations Millennium summit in 2000. They are the world's time-bound and quantified targets for addressing extreme poverty in its many dimensions – income poverty, hunger, disease, lack of shelter and exclusion – while promoting gender equality, education and human rights, and improving the lives of the poorest in the world. Halting and reversing the spread of HIV/AIDS by 2015 is the main target of MDG 6 (United Nations, 2012). The current study seeks to contribute to the attainment of this target by exploring HIV/AIDS-related information behaviour in order to generate the rich insights required to design and implement evidence-based, sensitive and responsive HIV/AIDS-related information services and products.

1.1.2 The HIV/AIDS epidemic

Human Immunodeficiency Virus (HIV) is a transmissible virus which affects the immune system by targeting certain white blood cells (CD4 cells) in the body. While it is predominantly sexually transmitted, it can also be spread through the sharing of equipment used for injecting drugs, transmission from mother to child (during childbirth and through breast milk), and contaminated blood and blood products.

Although the HIV virus is fragile and unable to live for long periods out of the human body, once inside, it invades the CD4 cells and tricks them into making copies of itself. The virus does this by disguising itself in a way that fools the CD4 cell into letting it in. Once in the nucleus, it integrates its own DNA into the DNA of the hijacked cell. Therefore, when the cell makes new proteins, it inadvertently makes new viruses; in effect, it becomes an HIV factory. Billions of copies of the virus are created daily in the body of an infected person. The newly formed viruses leave the infected cell to invade others and eventually take over the entire immune system (Usdin, 2003).

For a while, as HIV knocks out individual CD4 cells, the infected body remains strong enough to withstand attacks from the virus on a daily basis. At this stage the person is said to be HIV positive. Such a person looks healthy but can infect others if his /her body fluids - sperm, vaginal fluids, breast milk, or blood - are transferred to another person. When CD4 cell are destroyed to a level where the CD4 count falls below 200 cells per microlitre of blood, the body fails to fight off infections and becomes susceptible to opportunistic infections, which left untreated, will result in death. At this stage the person is said to have Acquired Immuno-Deficiency Syndrome (AIDS). It may take anything between 5 to 15 years after infection before AIDS becomes manifest.

To summarise: HIV is a life-long, potentially life-threatening condition which, when untreated, leaves an infected person more vulnerable to serious infections and cancers, and may progress to AIDS.

Although there is no cure for AIDS, antiretroviral drugs (ARVs) are available. ARVs can slow down the progression of AIDS and improve the quality of life for HIV-positive people. ARV medications cannot cure AIDS but can prevent HIV from reproducing inside the body, giving the immune system a chance to recover and fight back.

Furthermore, there is new evidence to suggest that ARVs can prevent heterosexual HIV transmission. Two randomized studies found that use of ARVs – pre-Exposure prophylaxis (PrEP) – by the HIV-negative partner in a discordant couple also reduced transmission substantially (Shelton, 2011). One major concern about ARVs is the associated undesirable side effects. However, when one considers that for people with AIDS the alternative is usually death, the drug benefits outweigh the risks.

AIDS was first diagnosed in the early 1980s, although HIV (the primary agent of AIDS) is believed to have existed from a much earlier date. The AIDS epidemic was first identified in the USA in 1981 in groups which formed the so-called H4 club, namely: Homosexuals, Heroin users, Haemophiliacs, and Haitians (Adams, 1989). It is argued that the retrovirus was discovered in 1983 by the French and the Americans in 1984. Over the last three decades medical research into AIDS has been intense but there is as yet no known cure. Although the origin of the virus remains uncertain, Seward (1991) suggested that there are indications, but no definite proof, that HIV came from a species of chimpanzee.

Scientists believe the virus originated in Africa although the epidemic did not initially emerge there.

Since its advent in 1981 to date, AIDS has remained a life-threatening pandemic with no known cure or vaccine, and treatment remains unaffordable or inaccessible for many people, especially vulnerable groups such as women, children and young people, sex workers, migrant workers and homosexuals.

1.1.3 The scale of the HIV/AIDS epidemic

Since it broke onto the scene three decades ago, HIV/AIDS has become one of the most serious disease epidemics of modern times. Over 60 million people have been infected with this retrovirus, and nearly 30 million people have died from AIDS-related causes (UNAIDS, 2010; UNAIDS, 2011). This is the equivalent of wiping out the entire population of Uganda.

According to UNAIDS (2011) World AIDS Day report, an estimated 34 million people were living with HIV worldwide by the end of 2010. This represented a 17% increase from 2001, and reflects the large number of new HIV infections. However, a significant expansion of access to antiretroviral therapy has helped to reduce AIDS-related deaths from 2.2 million in 2005 to 1.8 million in 2010 (WHO/UNAIDS/UNICEF, 2011; UNAIDS, 2011). Despite the progress that has been made in reducing AIDS-related deaths though, HIV/AIDS has continued to exceed all expectations in the severity and scale of its impact. Figure 1 below is an attempt to illustrate the severity of the disease.

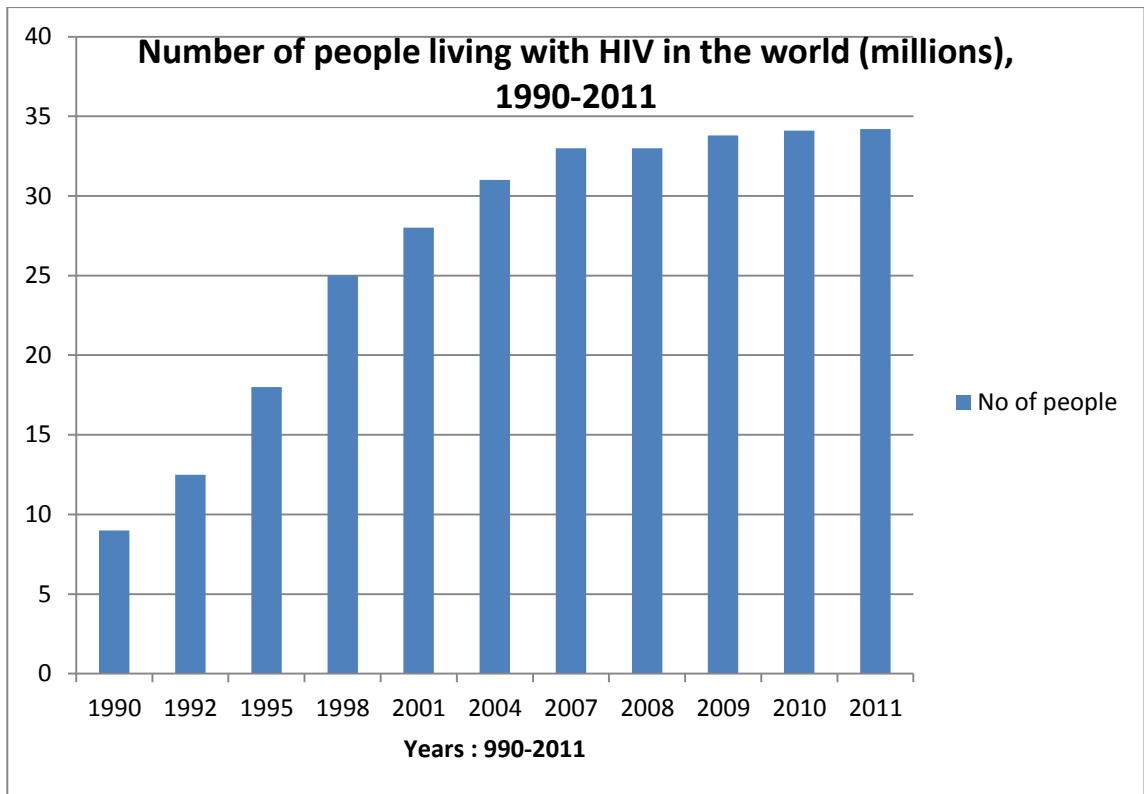


Figure 1: The global number of people living with HIV based on figures provided by the Millennium Development Goals Report 2012.

Sub-Saharan Africa carries the greatest burden of the epidemic with around 68 percent of all people living with HIV residing in this region (United Nations, 2012; UNAIDS, 2011). The UNAIDS World AIDS Day report (2011) has indicated that, while the epidemic in Asia has remained relatively stable, the number of people living with HIV in Eastern Europe and Central Asia has more than trebled since 2000.

Table 1: Statistics of the global HIV epidemic by the end of 2010 (WHO/UNAIDS/UNICEF, 2011).

Description	Estimate	Range
People living with HIV/AIDS in 2010	34 million	31.6-35.2 million
Proportion of adults living with HIV/AIDS in 2010 who were women (%)	50	47-53
Children living with HIV/AIDS in 2010	3.4 million	3.0-3.8 million
People newly infected with HIV in 2010	2.7 million	2.4-2.9 million
Children newly infected	390,000	340,000-450,000
AIDS deaths in 2010	1.8 million	1.6-1.9 million

1.1.4 The scale of the HIV/AIDS epidemic in the UK

Although the UK has seen a relatively small HIV/AIDS epidemic in comparison with some other parts of the world, the epidemic has, in relative terms increased dramatically since 1999 (Health Protection Agency, 2011).

According to the European Centre for Disease Prevention and Control/WHO Regional Office for Europe (2009), the UK has the fastest growing HIV epidemic in Western Europe. It is reported that since the first diagnosis of HIV was made 30 years ago, there have been 115,000 infections diagnosed in the UK alone. Of those people diagnosed, 27,000 have developed full blown AIDS and 20,000 have died (Health Protection Agency, 2011).

The Health Protection Agency (2011) also reported that, by the end of 2010, there were 91,500 people living with HIV infection and receiving HIV care in the UK, representing a nearly three-fold increase when compared to 26,088 in 2001.

It is estimated that more than 100,000 people will be living with HIV in UK by 2012, and almost a quarter will not be aware that they have HIV (Health Protection Agency, 2011).

The annual number of infections acquired within the UK has almost doubled from 1,950 in 2001 to 3,640 in 2010. Whereas, in 2001, only around 28% of HIV infections were probably acquired in the UK, by 2010 the proportion exceeded that of HIV infections probably acquired abroad 55% (3640) UK-acquired versus 45% (3020) acquired abroad. New diagnoses among heterosexuals who probably acquired HIV within the UK increased from 320 in 2001 to 1,090 in 2010, and these accounted for a third of all heterosexuals newly diagnosed in 2010.

Late diagnosis of HIV infection was cited as a major threat to tackling the UK's HIV/AIDS epidemic. For instance, it is reported that 68% of deaths in 2010 occurred among people diagnosed late, with most deaths occurring within 12 months of diagnosis (Health Protection Agency, 2011; House of Lords Select Committee on HIV/AIDS in the United Kingdom, 2011). Late diagnosis means that antiretroviral therapy is been delayed, which has grave health implications for the person diagnosed and grave cost implications for public health. Early diagnosis is overwhelmingly in the interest of public health

because it allows access to treatment, reduces transmission and reduces risky behaviour for those diagnosed (Health Protection Agency, 2011; House of Lords Select committee on HIV/AIDS in the United Kingdom, 2011).

Declining levels of knowledge about HIV/AIDS in the UK remains a major threat in their prevention and management. The House of Lords Select Committee on HIV/ AIDS in the United Kingdom (2011) reported that, although the success of the response to HIV in the 1980s was based partly on the profile of HIV/AIDS in the public mind, there has been no nationwide campaign since on the same scale. The Select Committee suggested that this may account for the widespread assumption that the danger has gone away. However, HIV is still a current and not a historical problem. For example, the House of Lords Select Committee on HIV/AIDS in the United Kingdom(2011), also reported that, despite the rising numbers of new infections in the UK, awareness about HIV/AIDS had fallen below the public radar, and knowledge about HIV had declined. Consistent with this finding was the National AIDS Trust's (2010) fourth study of people's attitude to, and knowledge about, HIV. That study found that levels of understanding about HIV transmission in the UK had fallen significantly since the year 2000. The study reported that in 2010, one in five adults did not realise that HIV is transmitted through sex without a condom between men and women; only 30% of adults could correctly identify, from a list of all possible routes, all the ways HIV can and cannot be transmitted; and an increasing proportion of adults incorrectly believed HIV can be transmitted by impossible routes such as kissing and spitting. The National AIDS Trust (2010) has responded to this challenge by encouraging all people to "act aware", in order to improve understanding about HIV/AIDS in the UK, prevent HIV transmission and stop prejudice.

The growing costs of HIV treatment, including hospital services and drug prescription, together with spending on prevention and social care, has significantly increased spending on HIV/AIDS (Mandalia et al., 2010; Health Protection Agency, 2011; House of Lords Select committee on HIV/AIDS in the United Kingdom, 2011). Mandalia et al.'s (2010) study on the rising cost of treating people living with HIV in the UK revealed that the annual population cost rose from £104 million in 1997 to £483 million in 2006, with a projected annual cost of between £721 and £758 million by 2013. They concluded that population costs are expected to continue to increase, partly due to longer survival and the relative lack of success of HIV prevention programmes.

HIV/AIDS-related stigma in the UK, like that in other parts of the world, stands as a road block to the fight against HIV at individual, community and national levels. For example, the Terrence Higgins Trust reports for the year 2000-2001 revealed that a large number of clients had been harassed, victimized, or discriminated against, because people assumed they were HIV positive (Terrence Higgins Trust, 2001). Some of the stigmatizing practices in the UK include: not wanting to share cups or cutlery with people living with HIV, ostracizing and /or physically abusing people living with HIV; and patients being refused treatment by health professionals such as doctors and dentists (Terrence Higgins Trust, 2001; House of Lords Select committee on HIV/AIDS in the United Kingdom, 2011). Responses to stigma, such as concealing one's HIV status, and being reluctant to seek medical attention, can have negative effects on public health; particularly on the prevention and management of HIV/AIDS. It is thus not surprising that the Department of Health's (2001) National Strategy for Sexual Health and HIV emphasizes the need to reduce the stigma associated with HIV/AIDS. In the light of these considerations, the researcher suggests that failure effectively to deal with the epidemic could have massive implications for public health both in the short and long term.

To summarize: the high costs of treatment, escalating numbers of new infections every year, late HIV diagnosis, a large proportion of people living with HIV who do not know that they are infected, and persistent high levels of stigma and discrimination, make HIV a tremendously expensive public health challenge which cannot be ignored.

1.2. Motivation for this research

The genesis of the idea to explore the extent to which information science research may be able to contribute to the fight against HIV/AIDS derives from the researcher's background and experience as a Ugandan citizen who, in addition to observing the devastating health, social and economic effects of HIV/AIDS on her country, has personal experience of the impact of the disease. Over twelve members of her family had succumbed to the disease by the time she started this study, and two close family members had recently been diagnosed with HIV. Consequently, the researcher was directly affected by HIV and experienced a number of associated challenges. These included emotional distress; lack of information that would have been valuable in helping her to support her relatives; the need to take leave from work; and economic challenges (including paying hospital bills, funeral

expenses, supporting orphaned children). Her prime motivation for conducting this study was her belief that accurate, reliable and up-to-date information could be a powerful tool in the prevention and management of HIV/AIDS. Some details of researcher's background are therefore relevant in understanding her suitability as a participant observer in the current ethnographic study of the information experiences of PI/ A HIV/AIDS.

The researcher's professional experience of information service provision has led her to the conviction that benefits can be derived when information management (the design, organisation and provision of information) facilitates people's access to, and use of, accurate information. She was therefore keen to explore the nature of HIV/AIDS-related information behaviour with a view to generating rich insights. Such insights could inform the design and implementation of HIV/AIDS-related interventions which could contribute specifically to effective access to, and use of, information relating to HIV/AIDS. An in-depth understanding of the real world 'lived information experiences' of PI/A HIV/AIDS's information behaviour within the broader context of people's lives could inform the planning and implementation of information-related interventions directed towards the prevention and management of HIV/AIDS.

The current threats to the prevention and management of HIV/AIDS in the UK, particularly the declining levels of awareness about HIV and its consequences, such as late diagnosis, increased infection rate, and increased costs of caring for people living with HIV, indicate that attempts to fight HIV cannot focus solely on the search for a vaccine, or a pharmacological cure. They must also take into account the complex social and cultural interactions that can both help and hinder the spread of the disease.

Information behaviour is a key component of such interactions, and understanding the way information behaviour affects, and is affected by, its broader context may be an influential factor in helping the fight against the disease. Although information alone cannot address the challenges posed by HIV, awareness of the realities of HIV/AIDS can constructively support efforts directed towards the prevention and management of the HIV/AIDS epidemic in the UK. Such efforts are particularly timely given the general decline in public knowledge about HIV referred to above.

National HIV programmes targeting two groups, namely men who have sex with men, and black Africans, have engaged in awareness campaigns, including the use of community-

specific media, leafleting, advertisements and posters. Such campaigns assume that, if relevant information is provided, it will create awareness. It is the view of the researcher that accessing and using health-related information is a complex process that is shaped by a wide range of factors which may not necessarily be obvious to individuals engaged in the planning and designing of health-related information interventions. Understanding the nature of HIV/AIDS-related information behaviour, and the factors that shape this behaviour, could inform the planning and design of future HIV/AIDS- related information interventions, including sensitive and responsive information services and products.

1.3. Aim of the study

The current study aims to generate understanding of the information behaviour of PI/A HIV/AIDS, including its drivers and inhibitors, in order to inform the design and implementation of evidenced-based information services directed towards the prevention and management of HIV/AIDS.

This aim translates into the following research objectives:

1. To understand the nature of the information behaviour of PI/A HIV/AIDS;
2. To identify the issues that affect their access to, and use of, HIV/AIDS-related information;
3. Based on (1) and (2) above, to develop a model of HIV/AIDS-related information behaviour;
4. Based (1) to (3) above, to identify implications for HIV/AIDS-related information management practice and strategy.

1.4. Structure of the thesis

This section outlines the structure of the thesis.

Chapter one presents the motivation for the research, and sets out the study's aims and objectives. Chapter two goes on to present a review of literature related to the topic of the thesis, including the key concepts in the sub-field of information behaviour.

This is followed by an overview of the models and theories which have been applied to study information behaviour and more specifically, health information behaviour (HIB). Gaps in the literature are highlighted.

Chapter three reviews research paradigms and designs available to the researcher, and identifies the conditions in which each can be applied to research with a view to positioning the current study within the theoretical and practical research framework. The chapter ends by identifying the most suitable research paradigm and research design for the current study.

Chapter four describes the research approaches applied in the study. It details what the researcher actually did, and explains how and why she did it. Chapter four also provides a justification for the choice of the research paradigm and design for the current study; it also describes the data generation process, including sampling methods, the study sample, ethics, and data analysis methods. Chapter four sets the background for Chapters five, six and seven, where first level data analysis is presented, and for chapter eight, where the results are interpreted.

Chapter five presents the first part of the findings. It describes the forms of HIV/AIDS-related information behaviour identified, such as hiding, seeking, avoiding, sharing and destroying information. The chapter includes quotations representing HIV/AIDS-related information experiences as narrated by the people infected with or affected by HIV/AIDS who constituted the study sample. This forms the evidence on which the findings of the current study are based.

Chapter six reports the second part of the findings, describing various kinds of post-HIV diagnosis reactions experienced by people in the sample (PI/A HIV/AIDS and the wider community) over time. The chapter focuses on post-HIV diagnosis reactions, including

both psychosocial reactions (such as shock and guilt), and reactions by other people that endanger the status and well-being of persons infected with, or affected by, HIV (e.g., being seen as a source of contagion, or being the subject of negative value judgements).

Chapter seven, the third and final part of the findings, focuses on the information world of PI/A HIV/AIDS. In the context of the current study, this world consists of HIV/AIDS-related information and information resources, as understood and described by persons infected with, or affected by, HIV/AIDS. The chapter provides insights into the 'lived information experiences' of PI/A HIV/AIDS, including the dilemmas, frustrations and 'disconnects' that directly or indirectly influenced their access to, and use of, HIV/AIDS-related information.

Chapter eight presents a higher order thematic analysis of the domains and sub-domains identified in chapters five, six and seven. While Chapters five, six and seven represent a relatively fragmented account of the HIV/AIDS-related 'lived information experiences', this chapter identifies more complex relationships between, and within, the domains and sub-domains. The chapter also relates these to the body of existing literature in order to generate a holistic view of the HIV/AIDS-related phenomena forming the focus of the study. The chapter examines interactions between HIV/AIDS-related post-diagnosis reactions (reactions by self and others), the information world, and HIV- and AIDS-related information behaviour, in order to generate an in-depth understanding of HIV/AIDS-related information behaviour. The intention in so doing is to generate a model of HIV/AIDS-related information behaviour.

Chapter nine starts by briefly summarising the research aim and approach. It then goes on to describe the key findings and the implications of the findings for health and information management practice, strategy and policy, for information professionals and for the wider scholarly community. It ends by highlighting the limitations of the study and presenting suggestions for future research.

1.5. Summary

This chapter has explained the genesis of, and motivation for, the research, and has set out the study's aims and objectives. It has also given an overview of the structure and content of the thesis.

CHAPTER 2-LITERATURE REVIEW

2.1. Introduction

This chapter builds on Chapter one, where the introduction and background to the research focus for the thesis are presented. The aim of this chapter is two-fold. First, it reviews literature related to the topic of the thesis, including the key concepts in the sub-field of information behaviour. Second, it positions the current study in the existing research framework by providing an overview of the models and theories which have been applied to study information behaviour and more specifically, health information behaviour (HIB). Gaps in the literature are also highlighted. The literature reviewed for this thesis was conducted systematically. Details of the literature review methods are available in appendix A.

This chapter sets the scene for Chapters three and four, which describe the philosophical and methodological position of the current study, before the results of the study are presented in Chapters five to eight.

2.1.1 Theories

Glanz et al. (2008) described a theory as a set of interrelated concepts, definitions, and propositions that present a systematic view of events or situations by specifying relations between variables in order to predict events or situations. Within the health context, theories are useful during various stages of planning, implementing and evaluating interventions, because they shape the pursuit of answers to ‘why?’, ‘what?’ and how? Theories, for example, can be used to guide the search for why people are not following public health and media advice, or not caring for themselves by adopting healthy ways of living. Thus, theories can help with what one needs to know before developing and organising an intervention programme, and to identify what should be monitored, measured, and compared in programme evaluations in order to explain behaviour and suggest ways to achieve behaviour change (Glanz et al., 2008).

Theories can be explanatory; that is, they can help to describe and identify why a problem exists, predict behaviour under defined conditions and guide a search for modifiable factors (such as attitudes, self-efficacy, social support and lack of resources, or change

theories) that guide the development of actions and interventions, and form a basis for evaluation (Institute of Medicine of the National Academies, 2002; Glanz et al., 2008).

Glanz et al.(2008) argued that health behaviour, and the related guiding factors, are far too complex to be explained by a single unified theory. Thus, models may draw upon a number of theories to help understand a specific problem in a particular setting or context. In other words, they are informed by more than one theory, as well as by empirical findings.

Concepts are major components of a theory; they are its building blocks or primary elements (Glanz et al., 2008). Concepts can vary in the extent to which they can be understood outside of a specific theory; hence, when they are developed or adopted for use in a particular case, they are called constructs (Kerlinger, 1986; Glanz et al., 2008).

Concepts used in the present study include information, information needs, information seeking, information behaviour and health information behaviour, and these are discussed below.

2.1.2 Information

Information is a concept about which no universal definition exists. As Case (2007) observed, part of the problem is that the word ‘information’ has been used to denote several different concepts in different disciplines. For example, the term information has been used to refer to sensory stimuli, mental representations, problem solving, decision making, an aspect of thinking and learning, states of mind, the process of communication, judgement about the relevance of information to information needs, the content of subject specialities, recorded knowledge, and particular objects which carry information (Case, 2002; Case, 2007). These many meanings of information have made it practically impossible for scholars to come up with a universal definition of information. Thus attempts have been made to define it from conceptual and physical points of view. Some of the definitions are highlighted below.

Dervin’s (1977) typology described information in terms of its types: objective, external information, that which describes reality; subjective, internal information, that which represents our picture or cognitive map of reality; and sense making information, that

which reflects the procedures and behaviour that allow us to move between internal and external information and to understand the world.

On the other hand, Ruben (1992) placed information conceptualisations into three orders. These include: the environmental artefacts and representations which consist of stimuli, messages or cues waiting to be attended to; internalised and individualised appropriations and representations, that is information that is transformed, and configured for use by a living system; and information that is socially constructed, negotiated, validated, and specifically, the social context of information.

Buckland's (1991) typology portrayed the use of the word information as falling into three categories: information as a process; information as knowledge; and information as a thing. While MacCreadie and Rice (1991) identified four conceptualisations of information: information as a resource; information as data in the environment; information as a representation of knowledge; and information as part of a communication process.

Although the distinctions these authors make are useful in illustrating the attributes of information, they fall short of a specific definition for the term information because they only show the distinct use of the term rather than offering a single definition. Given the widespread disagreement on what would constitute a general definition of information, the researcher adopted Case's (2007) view of treating information as a primitive concept that is so basic to human understanding that it requires no tight definition. Perceiving information as a primitive concept, as "*any difference that makes a difference*" (Case, 2007:p. 63) in the structure of the human mind allowed the researcher to review previous studies on information seeking and information behaviour without any restrictions. Such a stance was appropriate for the current study because it is concerned with a broad view of information phenomena that fits both real life and empirical studies of real life, and not with establishing a philosophical distinction. Consistent with this reasoning is Case (2007), who argued that defining information in an absolute way is not entirely necessary for the study of information phenomena to start with. That broad understanding of information in mind, the researcher reviews work on health information behaviour, and HIV/AIDS-related information behaviour, in order to generate knowledge that can be used to enhance the role of information in the fight against HIV/AIDS.

2.1.3 Information needs

Dervin (1986) defined an information need as a compulsion to make sense of a current situation. Kuhlthau (1993) suggested that an information need arises from an awareness of something missing which necessitates seeking for information that might contribute to understanding and meaning. Thus, satisfying an information need is a dynamic process during which absorbed knowledge may lead to renewed information needs (Ford, 1980; Kuhlthau, 1993a). However, Wilson (1997) stated that, while researchers fret over the definition of information needs, most of the time they are studying information-seeking behaviours. Belkin and Vickery (1985) suggested that the difficulty with defining information needs was partly because information needs exists inside someone's head, which makes observing them problematic. Wilson (1997) suggested that, since most information needs could be accounted for by more general needs, the notion of an information need was unrealistic.

2.2. Existing theories and models

The interdisciplinary nature of the current study warranted a review of models within health psychology and information science, with a view to identifying a theory that could explain HIV/AIDS-related information behaviour. Although the review is not exhaustive, well-known and widely applied health behaviour and information-seeking behaviour models and theories are reviewed in order to identify a model that may be employed to explain HIV/AIDS-related information behaviour. This review is important because different theories are best suited to different contexts and phenomena in which research takes place. Consistent with this reasoning is Glanz et al. (2008), who observed that effective health education depends on marshalling the most appropriate theory and practice strategies for specific situations.

2.2.1 Models of information behaviour: general models not specific to health

Case (2007) defined information seeking as the conscious effort to acquire information in response to a need or knowledge gap; while Johnson (1997a) defined it as the purposive acquisition of information from selected information carriers. Kuhlthau (1993a) argued that information seeking is experienced by users as a process of construction, in which the user actively pursues understanding and meaning from the information encountered over a

period of time. She described information seeking as a process which involves the total person, incorporating thinking, feelings and acting in a dynamic process of learning. Thus, information seeking is a holistic experience which encompasses the user's thoughts, actions and feelings, all of which are interwoven into a complex montage rather than a separate, distinct entity (Kuhlthau, 1993a).

Wilson (2000) described information seeking as the purposive seeking for information in which an individual may interact with manual information systems such as a newspaper or a library, or with computer-based systems such as the World Wide Web, in order to satisfy some goal. It should be noted that all the definitions above emphasise that information seeking is a purposive activity that results in information use. This limits the definition's applicability to the broad range of research being currently conducted on human use of information because, as Case (2007) rightly observed, not all information seeking boils down to information use.

Bates (2010) described information behaviour as a term used to describe the many ways in which human beings interact with information; in particular, the ways in which people seek and utilise information. Information behaviour is also the term used in Library and Information Science to refer to a sub-discipline that engages in a wide range of types of research conducted in order to understand the human relationship with information (Bates, 2010). On the other hand, information seeking behaviour is concerned with determining user's information needs, searching behaviour and subsequent use of information.

Bates (2010) pointed out that studies on information behaviour were initially referred to as user studies, or studies of information seeking and gathering, or studies of information needs and uses; for example, Julien's content analyses of the information needs and uses of literature (Julien, 1996; Julien and Duggan, 2000). At that time, the term 'information seeking' was used to include all kinds of research on people's interaction with information. However, researchers felt that information seeking suggested only explicit efforts to locate information and did not include the many other ways people and information interacted; hence they opted to use the term 'information behaviour' in the early 1990s (Case, 2007; Bates, 2010).

Hepworth (2007) in his paper on knowledge of information behaviour and its relevance to the design of people-centred information services and products, underscored the value of

research on different dimensions of Information Behaviour (IB) in generating insights that facilitate the development of information products and services that meet the requirements of specific groups of people. For example, IB research generated knowledge that was used by information science practitioners and researchers in the development of information literacy standards and guidelines (Armstrong et al., 2005; Hepworth, 2007).

Information behaviour is a broader term that encompasses information seeking and behaviours that are passive (Case, 2007). According to Wilson (1999), information behaviour refers to those activities a person may engage in when identifying his or her own needs for information, searching for that information in any way, and using or transferring that information. He further describes information behaviour as the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking and information use. In his view, information behaviour includes face-to-face communication with others, as well as passive reception of information; for example, television advertisements.

Although the above definitions are intended to define information behaviour, they are in most cases restricted to depictions of information seeking in its various forms. The only exception is Case (2007), who suggested looking at information behaviour more holistically and perceiving IB in terms of a broad range of relevant human behaviours dealing with information.

Case's (2007) conception is appropriate for the current study, which set out to explore information behaviour more holistically in the context of a life-threatening and stigmatising health condition - HIV/AIDS. The current study was motivated by Case's (2007) review of literature on information seeking research over the past decade, which indicated that non-work contexts had received inadequate attention by investigators as though activities outside the job did not matter. The current study seeks to fill this gap by exploring the patterns of information behaviours within the every-day life contexts of people infected with, or affected by, HIV/AIDS (PI/A HIV/AIDS).

According to Wilson (1999), research on information behaviour originated in 1941, and since then it has grown rapidly. Wilson (1999) pointed out that researchers' inability to build on prior research hindered the development of a body of theory-related to empirical findings necessary for further research. He cited adopting a positivist tradition (where

quantitative methods were adopted), which entailed counting the number of visits to libraries, personal subscriptions to journals, etc., to the study of human behaviour and ignoring allied work in related areas that could offer more robust theoretical models of human behaviour; and infancy of the models of information behaviour as major hindrances to theory development in information behaviour research.

Wilson (1999) observed that the situation was now changing, especially with the adoption of qualitative methods to study human behaviour; and the adoption of models, such as those of Wilson, Dervin, and Ellis, for further research by other investigators.

Although the attendees of the Information Seeking in Context (ISIC) conference advocated research that studied information behaviour beyond traditional designs in order to gain a much fuller sense through rich, detailed qualitative study, the majority of studies reviewed in this research used quantitative survey methods. This observation is consistent with Case (2002), who noted that many studies in information seeking have been done using quantitative methodologies. It is further confirmed by Lambert and Loisel's (2007) review of literature on health information-seeking behaviour, which revealed that approximately 60% of the articles were quantitative studies, particularly dealing with information seeking styles; while 15% were qualitative studies, particularly focusing on type and source of information preferred.

The use of quantitative approaches to study health information seeking behaviour has been criticised on the grounds that the complexity of human information behaviour cannot be reduced to mere quantitative phenomena (Wilson, 1999 ; Case, 2007). Researchers reacted to this criticism by conducting qualitative studies using methods such as interviews and focus groups to study human information behaviour, particularly information seeking. Mixed method approaches have also been applied on a small scale to the study of the phenomenon. Although such approaches increased our understanding of information seeking, however they often lack depth and rich insights into the information behaviour of the groups they are applied to. This inadequacy stems from the fact that such approaches often lack the framework to support immersion and participation in the research setting. Thus they rarely generate in-depth and intimate understanding of the information experiences from the point of view of the participants.

The current study addressed that gap by applying ethnographic approaches (see Sections 3.4, 4.2 and 4.3) to the study of sensitive, personal and, in some cases distressing, HIV/AIDS information experiences of PI/A HIV/AIDS in the UK in order to generate a much fuller and deeper sense of information behaviour in an HIV/AIDS-related information context. It is the view of the researcher that studying this specific context may help to understand the much nuanced ways in which people might interact with, and perceive, information in life-threatening and stigmatising contexts.

Research using ethnographic approaches to study the information behaviour PI/A HIV/AIDS is limited. The approach has been used to investigate other issues relating to HIV/AIDS, such as the relationship between sex, stigma, drugs and the spread of HIV (Farmer, 1992; McCoy et al., 1996; Parker and Ehrhardt, 2001a; Parker and Aggleton, 2003; NIMH Collaborative HIV/STD Prevention Trial Group, 2007).

A number of studies in Librarianship and Information Science have also used ethnographic approaches to study information needs and aspects of information behaviour – but in other groups. These include investigations of the information needs of general practitioners (Shapiro, 1989); technical support workers (Cunningham et al., 2001); information seeking of online investors and women with breast cancer (Kingford and Willimson, 2004); and the information behaviour of attendees at community clinics (Pettigrew, 1999).

The research approach and design of this study were selected to map onto key features of the research phenomenon and context. These features included the following:

- We do not yet have models of the information behaviour exhibited by this particular group of people, of the factors affecting them, or of their effects, that are sufficiently well developed and robust to be able to suggest variables, measures and relationships suitable for deductive testing. For this reason, an inductive research approach was adopted, based on qualitative data, in an attempt to understand experiences from the perspectives of the people involved, and in their own terms, rather than gathering quantitative data on pre-defined variables.
- Studying information behaviour relating to HIV/AIDS-related information entails participants revealing very personal experiences and perceptions relating to sensitive issues in which they may feel considerable vulnerability. For this reason, an ethnographic research design was adopted. Such a design entails interacting with

participants in their own environment in as naturalistic a context as possible, attempting to share as far as possible their day-to-day experiences, in order to gain insights into their thoughts and behaviour from their own perspectives.

- Ethnography is particularly well suited to unearthing complex phenomena, in marginalised social settings, among hard to reach populations. It has the potential to uncover what might otherwise remain hidden aspects of social experience, particularly in settings characterised by stigma and discrimination. Sections 3.4, 4.2 and 4.3 in subsequent chapters consist of detailed accounts of how and why ethnographic research approaches were applied to the current study.

Wilson (1999) described a model as a framework for thinking about a problem which may evolve into a statement of the relationships among theoretical propositions. Case (2007) pointed out that models focus more on specific problems than on theories. Wilson (1999) observed that most of the models in the field of information behaviour are in the form of diagrams that attempt to describe an information seeking activity, the causes and consequences of that activity, and the relationships among stages in information seeking behaviour. Wilson (1999) observed that such models rarely advance to the stage of specifying relationships among theoretical propositions; rather, they are at a pre-theoretical stage. Wilson's (1999) review of models in information behaviour research indicated that models of information behaviour appear to be fewer than those on information seeking behaviour or information searching.

The work of researchers such as Ikoja-Odong and Mostert (2006), Wilson (1999), Case (2007), Bates (2010), and Godbold (2006), identified numerous models of information seeking behaviour. The purpose of this review is not to cover exhaustively all the models of information seeking and behaviour. Thus the models discussed in below are included in the review because they are more fully developed; i.e., they attempt to depict and explain a sequence of behaviour by referring to relevant variables rather than as a sequence of events.

Wilson's (1981) model

The aim of this model was to outline various areas covered by what Wilson (1981) proposed as information seeking as opposed to information needs. The model suggests that information-seeking behaviour arises as a consequence of a need perceived by an information user, who makes demands upon formal or informal sources or services which result in success or failure to find relevant information. Success leads to utilisation of information, which results in partially or fully fulfilling the perceived need. On the other hand, should failure occur, the search process is repeated. Wilson's (1981) model also indicates that part of information behaviour may involve other people through information exchange, where useful information is passed to other people rather than being used by the person himself or herself. Wilson's (1999) model depicted information seeking as the main information behaviour, but made no attempt to describe forms of information behaviour other than information seeking. Wilson (1981) acknowledged that his model only provides a map of the area, and draws attention to research gaps, but suggests no causative factors in information behaviour, and consequently it does not directly suggest hypotheses to be tested.

Wilson's (1981) second model

In his second model, Wilson (1981) made two propositions: an information need is not a primary need but a secondary need that arises out of needs of a more basic kind and suggested that in the effort to discover information to satisfy a need, the enquirer is likely to meet barriers of different kinds. Wilson drew upon definitions from psychology and proposed that a need can be defined as physiological, cognitive and affective. He noted that the context of these needs may be the person him- or herself, or the role demands of the person's work or life, or the environment within which that life or work takes place (Wilson, 1999a). He suggested that the barriers that impede the search for information arise out of the same set of contexts. His model has been described as a macro-model, or model of gross-information seeking, that suggests how information needs arise and what may prevent the actual search for information. The model embodies an implicit set of hypotheses that can be tested; however, it has been criticised on the grounds that its hypotheses are only implicit. It is also criticised for not providing any indication of the processes whereby context has its effect on the person, nor the factors that result in the perception of barriers, and whether or not the various assumed barriers have effects on the

motivation of the individual to engage in information behaviour other than information seeking per se.

Wilson's (1996) model of information behaviour

Wilson's (1996) model of information behaviour is a major revision of the 1981 model. It draws upon research from a variety of fields, such as decision making, psychology, innovation, health communication, and consumer research, in order to explain how needs prompt people's information seeking behaviour, source preference, and why some information seekers pursue a goal more successfully than others (Wilson, 1997; Wilson, 1999 ; Case, 2007). Although the model describes general information behaviour as opposed to information seeking, it retains the basic framework of the 1981 model; the person in context remains the focus of the information need, the barriers are represented by intervening variables, and information seeking is the only information behaviour identified.

Wilson's 1996 model attempts to explain the role played by various activation mechanisms or motivators in influencing the 'what', 'how' and extent of the search. He identified five types of variables including; psychological disposition; demographic background; factors related to one's social role; environmental variables; and characteristics of resources, that determine people's motivation to seek information.

The model also identifies other types of information seeking behaviour, including passive attention, passive search, active search, and on-going search (Wilson, 1997; Ikoja-Odong and Mostert, 2006; Case, 2007). This model has been criticised on the grounds that it confines itself to depictions of information seeking behaviour and makes no attempt to explain explicitly the role of intervening variables, such as source characteristics, psychological and environmental factors, that shape information behaviour generally, rather than just information seeking. The model also lacks deeper levels with finer details of the complexities of human information behaviour, particularly in an everyday-life information context.

Krikelas's (1983) model

Krikelas' (1983) model was one of the first depictions of explicit information seeking behaviour that emphasised the importance of uncertainty as a motivating factor, and the

potential for an information seeker to retrieve an answer from their own memory or those of nearby persons (Case, 2007). The model contains 13 components and depicts causal processes that generally flow downwards with some provision of feedback loops. Krikelas (1983) suggests that a user perceives a need within the context of his or her environment. According to him, information can be anything that reduces uncertainty, while an information need is the recognition of the existence of uncertainty in the person or in their work-related life. Krikelas suggests that some needs could be stored in memory or physical media for future attention, while other needs are immediate and urgent. Krikelas (1983) suggests that, in order to meet an information need, the searcher must consciously consult an information source. The model is a simple one way flow-chart in which all the arrows travel in one direction. This has attracted the criticism that simplicity leads to oversimplification (Case, 2007). Although seemingly applicable to ordinary life, it is in practice a library search model that depicts decision points along the paths to either a reference desk or the library collection. Case (2007) suggests that Krikelas's (1983) model is perhaps more applicable to the information seeking of students or professionals in some work-related context.

Dervin's (1999) sense making theory

Dervin's (1999) sense making theory was developed over a number of years and cannot be seen simply as a model of information seeking behaviour. Consequently, Dervin (1999), Case (2007) and Wilson (1999) have described the sense making theory as a set of assumptions, a theoretical perspective, a set of research methods and a practice designed to provide a framework for making sense of reality that is assumed to be both chaotic and orderly. Dervin suggested constituent elements, namely: a situation in time and space, which defines the context in which the information needs arise; a gap which identifies the difference between the contextual situation and the desired situation, such as uncertainty; an outcome, that is the consequence of the sense making process; and a bridge, that is some means of closing the gap and through which sense-making is implemented. Dervin's sense-making in some cases was depicted using a bridge-building metaphor or a triangle.

Wilson (1999) suggests that the strength of Dervin's model lies partly in its methodological consequences, particularly its potential to lead to a way of questioning that can reveal the nature of a problematic situation, the extent to which information serves to bridge the gap of

uncertainty and confusion, and the nature of outcomes from the use of information. When applied consistently, such questioning can potentially generate insights that can influence information service design and delivery.

Dervin's Sense Making theory is useful insofar as it increases understanding of the importance of sense making in motivating information seeking and information needs. For example, Hepworth (2004) used Dervin's (1999) micro-timeline interview to study the information needs of informal carers. Although Dervin (1999) increases our understanding about the need to constantly make sense of the unruly and problematic world, through seeking information to bridge the gap, she does not pay attention to the challenges, dilemmas, frustrations and disconnects people may face in trying to close the gap. The model does not illustrate how such complexities could influence efforts to access, and use, information to close the gap. The model also assumes that people are always in a position to make sense of a situation. However, some of the time people may be happy not to make sense of the situation, especially when engaging in information seeking is perceived to be costly and risky. For example, when people anticipated that seeking HIV/AIDS-related information could result in emotional and physical risk such as abuse, stigma and discrimination, they opted to avoid seeking information, seek it clandestinely, or even destroy information.

The above discussion emphasises the need to conceive information behaviour as any endeavours to engage, or not engage, with information, as people construct their life and cope with a boisterous world.

Dervin's (1980) study that found that patients' information seeking and use was predicted by their descriptions of their situations, but does not attempt to explain how people navigate the gap within health-related life-threatening contexts. The model is also criticised for not capturing the ingredients within the person and in the environment that trigger information behaviour. For example, Savolainen (1995) observed that, although the focus of Dervin's (1986) Sense Making theory on the individual sense maker is useful, it is confined to information seeking and is too generic.

Leckie's (1996) model

Like Krikelas (1983), Leckie et al.'s (1996) model is restricted to a range of people: professionals such as doctors, lawyers and engineers. It features six factors connected by arrows. The model is depicted as flowing from top to bottom, with the causal processes beginning on the top with work roles which influence tasks. The model is confined to professionals such as doctors, lawyers and engineers, which explains why work roles and tasks are perceived to be the prime motivators of information seeking.

The model is restricted to information seeking and pays inadequate attention to the role of the nature of information, mental and emotional states, or the perception of other people's attitudes and reactions, in shaping information behaviour. Leckie et al.'s (1996) diagram has limited applicability to everyday-life information seeking because it is clearly characteristic of work-related information seeking processes. The model identified aspects of the need situation such as context, frequency, predictability, importance, and complexity. Leckie et al.'s (1996) model suggests that need creates an awareness of information sources or content, and thus motivates the person to examine those. Like Johnson (1997a), Leckie et al.'s (1996) model suggests that variables such as familiarity and prior success with the source, trustworthiness, packaging, timeliness, cost, quality and accessibility of the sources are important in motivating information seeking among professionals.

Ellis' (1998) model

Ellis' (1998) model is an empirically-based model of common action associated with scholarly information seeking (Wilson, 1999 ; Bates, 2010). The model describes features that characterise information seeking as opposed to stages. The features included:

- Starting (means employed by a user to begin seeking for information);
- Chaining (following footnotes and citations in known material);
- Browsing (semi-structured searching);
- Differentiating (filtering the amount of information received using known sources);
- Monitoring (keeping up-to-date or current awareness searching);
- Extracting (selecting relevant materials from an information source);
- Verifying (checking the accuracy of information);

- Ending (tying up loose ends).

Despite the fact that Ellis does not subscribe to a sequenced set of stages, Wilson (1999) suggested that a certain pattern is embedded in process as starting must initiate a process and ending must close it.

Kuhlthau's (1991) model of the Information Seeking Process

Kuhlthau developed a model of the Information Seeking Process (ISP) that describes definite stages in the information seeking process, and also takes into account the information seeker's feelings, thoughts and actions (emotional, cognitive and physical experiences) at different stages of the search process (Kuhlthau, 1991 ; Kuhlthau, 1993a). The model of the information search process is derived from five studies investigating common experiences of actual library users: students in universities, colleges, and secondary schools - most of whom were responding to an imposed rather than a personally initiated information need (Kuhlthau, 1991). The model was enriched by a study of public library users with personally initiated or job problems.

According to Kuhlthau's (1991) model, there is a progression from recognising an information need, to identifying a general topic, to exploring information on a general topic, to formulating a specific focus, to gathering information pertaining to the focus, and then to completing the information search.

Kuhlthau (1991) suggests that movement during the information seeking process is caused by a series of choices made through a complex interplay of three realms of activity: physical (the actions taken); cognitive (thought about the process and content); and affective (the feelings experienced). The model posits that the search process is an active process engaging the cognitive processes of the seeker that are triggered by feelings of uncertainty, particularly during the exploration stage.

Kuhlthau (1999) suggests that the affective symptoms of uncertainty, confusion and frustration, prevalent in the early stages, were associated with vague, unclear thoughts about a topic or problem. Thus the information seeking process is initiated by uncertainty resulting from lack of understanding, with the information seeker feeling frustrated and in

doubt; it ends with the final stages where the seeker is satisfied, confident and relieved (Kuhlthau, 1999).

The model is useful in generating understanding about the complex information search process in the context of imposed information seeking processes: students researching, organising, writing and presenting a paper or an assignment. Thus it may be incorporated into user education programmes to educate people about their own evolving search processes and understand feelings which affect their information use. The model is also useful because it goes beyond the cognitive aspects to examine the feelings users commonly experience. Thus a shift from merely devising better means for orienting people to sources and technology, to addressing issues of uncertainty and anxiety, is suggested.

While lack of familiarity with sources and technologies, and the very nature of the information seeking process itself, may create a climate for potential anxiety; being faced with a life-threatening, debilitating and stigmatising health condition may result in extreme emotional distress way before the information search process is even contemplated.

Although Kuhlthau (1999) takes into account the affective aspects of the information seeker's experience, she does not attempt to illustrate with empirical evidence ways in which feelings shape the user's information behaviour. In light of these considerations, the ISP model may not be adequate in everyday-life contexts, especially those characterised by stigma, discrimination and emotional distress. The current study sets out to fill this gap.

Savolainen's (2005) Everyday Life Information Seeking model

Savolainen's (2005) model of Everyday Life Information Seeking (ELIS) was developed based on his interviews with ordinary citizens pursuing non-work activities. Savolainen's model offers a shift of attention from work-related processes to the study of everyday-life information seeking, and suggests that work and non-work related information seeking activities are complementary. Savolainen's predominantly sociological model emphasises the role of social and cultural factors in shaping people's ways of preferring and using information (Savolainen, 1995; Savolainen, 2005). The model incorporates concepts such as social capital, and cognitive capital; it also considers how socio-economic factors affect ways in which individuals identify projects, budget their time, keep order, and make sense

of their lives. Although the model has been useful in studying the broad scope of human lives, it has been criticised for only providing a depiction of a causal process rather than a list of concepts that must be explored in an in-depth interview (Case, 2007).

Godbold's (2006) model of information behaviour

Godbold's (2006) model of information behaviour focuses on the depiction of information behaviour and navigation of the gap. The model is not only an extension of Wilson's nested models of information behaviour, but also incorporates Wilson's earlier models, as well as those of Dervin and Brookes. It suggests that an individual begins with a knowledge state which gets modified when a person passes through an information behaviour wheel. The model depicts a multidirectional process passing through a gap, as a way of overcoming the notion of sequential stages depicted by researchers such as Kuhlthau and Ellis.

The model also includes other forms of information behaviour such as hiding, avoiding, and destroying information that extend beyond information seeking alone. Godbold's (2006) model makes the gap explicit and suggests three strategies for dealing with it: building a bridge; closing a gap; and taking a different path for closing a gap.

Godbold's (2006) model suggests that, although the gap prompts information behaviour, information behaviour such as information seeking, creation, and spreading, can occur without a gap. Research has shown that people may take pleasure in information behaviour for its own sake (Krikelas 1983; Savolainen, 1995), while other people may wish to do nothing about the gap they experience (Miller, 1991; Case et al., 2005). Godbold (2006) suggests that information behaviour is not necessarily driven by a desire to satisfy discrete needs; rather, it includes any information encounter in an individual's on-going engagement with, and construction of, their world. Although the model has increased our understanding of other forms of information behaviour that people can engage in while closing the gap, it does not fully explore the gap based on empirical evidence. This explains why Godbold (2006) suggested that research, possibly involving in-depth interviews, should be carried out to explore the gap itself; particularly, on how people navigate the gap, and the multiplicity of intertwining paths.

Foster's (2004) non-linear model of information seeking behaviour

Foster's (2004) non-linear model of information seeking behaviour, which was developed based on a sample of interdisciplinary researchers (in the faculties of Arts and Humanities, Social Sciences, Engineering and Medicine), describes three core processes (opening, orientation and consolidation); and three levels of contextual interaction (internal context, external context and cognitive approach); that are used to show that information seeking is non-linear, dynamic, holistic and flowing.

In the model, opening was identified as corresponding to a process of moving from a state of orientation to actually seeking, exploring and revealing information. Thus, opening is a non-linear component representing a collection of activities which Foster describes as 'Breadth Exploration and Eclecticism' (Foster, 2004). He identified 'Breadth Exploration' as a conscious expansion of searching that allowed exploration of every possibility; that is, different information types, sources, concepts and disciplines. In turn these facilitate orientation processes, such as choice of keywords, selection of sources, and initiation of other core processes. On the other hand, 'Eclecticism' was perceived to provide a conceptual approach to finding information through a combination of active, passive and serendipitous information acquisition (Foster, 2004).

Foster identified orientation activities, such as identification of key research themes, interdisciplinary communities, latest opinion, sources, key words and picture building, that are important in problem definition. He suggested that activities and strategies identified in the opening could also lead back into the orientation process; while opening could lead back into further orientation or consolidation.

The model suggests that interdisciplinary researchers engaged in judging and integrating the work in progress and deciding whether information is necessary; a process that is described by Foster as 'consolidating' (Foster, 2004). His argument is that in interdisciplinary research, consolidation looped in, and intertwined with, orientation; he suggested that this may not be the case with other kinds of research. The model also highlighted the importance of the cognitive approach, and internal and external contexts, in the interdisciplinary researcher's information seeking endeavours.

Although the model is valid in so far as it portrays information seeking as a non-linear process within an academic context, it could not be applied to the current study due to the

following reasons: 1) The model is confined to information seeking and does not reflect the many other ways people and information interact: and 2) The complex information experiences, including information behaviour, of persons infected with HIV cannot be explained by a model developed in an academic context because their aims for engaging in information behaviour are different. Researchers want to find information about a topic; PI/A HIV/AIDS want to find life-saving information. Unlike researchers, PI/A HIV/AIDS have to deal with emotional distress, and calculate the cost of engaging in information behaviour, before starting the information behaviour journey.

2.2.2 Summary

Most of the models reviewed direct their effort to describing the process of a purposeful acquisition of information, and portray information seeking as the sole form of information behaviour. The only exception is Godbold's (2006) information wheel, which includes other modes of information behaviour such as creating, destroying and hiding information. The model also seems to indicate awareness that a user may make use of a variety of information sources, services, and channels, or even contact individuals, to solve a problem.

Models such as Kuhlthau's (1993b) Information Search Process, and Ellis' (1998) Information Seeking Characteristics, although invaluable in understanding scholarly information seeking, have been criticised for portraying the information seekers' actions in a sequential fashion; i.e., they are predominantly similar to conventional flow-charts; however, human behaviour is not always sequential (Godbold, 2006; Case, 2007; Johnson, 2009). This endangers their practical application, since people do not necessarily apply sequential, orderly, mechanistic approaches to problem solving.

The majority of the models reviewed, with the exception of Savolainen (2005), are confined to information seeking and behaviour undertaken by people in work-related and/or academic contexts, where individuals' information seeking efforts are directed to a particular research project or specific work tasks. In such cases, information seeking entails presenting an information system with defined information search terms, using a search strategy to look for information for the topic being researched, or for a work task. Thus everyday-life information behaviour has received inadequate attention.

The review also revealed work on everyday-life information seeking, such as Savolainen (2005), that made no attempts to account for information behaviour in life-threatening and stigmatising contexts.

The inadequacy of the information seeking and information behaviour models generated the need to review models and theories applied to health information behaviour, which is undertaken in Section 2.2.3 below.

2.2.3 Health behaviour theories and models

Conner and Norman (2005) broadly define health behaviours as any activities undertaken for the purposes of preventing or detecting disease, or for improving health and wellbeing. They observed that performance of health behaviours was responsible for both morbidity and mortality. A considerable body of research has indicated that the key factors that determine individual propensity to undertake health behaviour include: demographic factors; social factors; emotional factors; perceived symptoms; factors relating to access to medical care; personality factors; and cognitive factors (Armitage and Conner, 2000; Conner and Norman, 2005). Research has indicated that socio-demographic variables are not readily open to change; consequently, researchers have focused their attention on social cognitive variables to potentially explain individual differences in health behaviour that have previously been attributed to social demographics (Armitage and Conner, 2000). This focus is based on the assumption that social behaviour is best understood as a function of people's perception of reality, rather than as a function of an objective description of the stimulus environment. This accounts for the importance of social cognitive determinants of health behaviour as an area of study for health psychologists.

Glanz et al.(2008) reported, in a review of 116 theory-based articles published between 1986-1988 in two major health education journals, that they had identified 51 distinct theoretical formulations. At that time, the three most frequently mentioned theories were: Social Cognitive Theory (SCT); the Theory of Reasoned Action (TRA); and the Health Behaviour Model (HBM).

A review of 526 articles from 24 different journals in health education, medicine and behavioural science, published from mid-1992 to mid-1994, by Glanz et al. (1996), identified 66 theories and models in use, of which 21 were mentioned eight times or more.

Two-thirds of the total instances of theory use were accounted for by the most frequently - mentioned theories including HBM, SCT, self-efficacy (Bandura, 1997), and the Theory of Reasoned Behaviour/Theory of Planned Behaviour (TRB/TPB).

The 1999 and 2000 review of all the issues published in 12 journals in health education, behaviour and preventive medicine that was conducted by the same authors, identified the ten most used theories or models. The first two, and by far the most dominant were, SCT and the Transtheoretical Model (TTM)/stages of change. The remainder of the ten were the HBM, social support and social networks, patient provider communication, TRA and TPB, stress and coping, community organisation, ecological models and diffusion of innovations (Glanz et al., 2002). Glanz et al.'s (2008) most recent review of theory in use in published research between 2000 and 2005, identified TTM , SCT and HBM as the most often used theories for understanding behaviour and behaviour change. Overall, the same theories dominated as was the case in 1999 and 2000. In light of the above, the researcher has reviewed the four most commonly used models of health behaviour change, and these are described below.

Health Belief Model

Since the early 1950s, the Health Belief Model has been one of the most widely used conceptual frameworks in health behaviour research, both to explain change and maintenance of health-related behaviours, and as a guiding framework for health behaviour interventions. Hochbaum's (1958) health belief model is a psychological model that attempts to predict health behaviours. The model was developed based on studies on the uptake of tuberculosis X-ray screening by social psychologists in the United States (Glanz et al., 2008). It was developed to explain the widespread failure of people to participate in programmes to prevent and detect Tuberculosis. It was later employed in the public health arena to predict who would utilise screening tests and /or vaccinations (Rosenstock, 1966; Janz and Becker, 1984; Redding et al., 2000). The health belief model postulates that a strong relationship exists between beliefs, socialisation and behaviour.

The model is based on understanding the likelihood of experiencing a health problem, the severity of the consequences of that problem, and the perceived benefits of health behaviour, in combination with its potential to motivate health-related action (Becker, 1974; Redding et al., 2000; Abraham and Sheeran, 2005; Conner and Norman, 2005;

Glanz et al., 2008). Thus, the likelihood that someone will take action to prevent illness depends on: their evaluation of the chances of getting the condition (perceived susceptibility); their perception of the seriousness of the illness, and its consequences (perceived severity); their evaluation of how well an advised action will reduce risk (perceived benefits of engaging in health behaviour); their evaluation of how difficult an advised action will be (perceived barriers); events or strategies that increase their motivation (cues to action); and confidence in their ability to take action.

The health belief model has been applied to the prediction of a broad range of health behaviour, such as: preventive health behaviour, which includes health-promotion (e.g., diet and exercise) and reducing health risk (e.g., not smoking), as well as vaccination and contraceptive practice; and sick role behaviour (e.g., compliance to recommended medical regimens).

Although HBM's principles are useful in guiding our understanding of protective and preventive health behaviour, and have been applied in interventions focusing on reducing and/or changing risky sexual behaviours, including AIDS prevention; it may not be applied to the study of complex health information behaviour of people experiencing a life-threatening, distressing and stigmatising illness, that is, HIV/AIDS. The nature of transmission, the social construction of HIV/AIDS, the absence of a vaccine or cure, as well as the length of time one lives with HIV/AIDS, makes it unique. The reality for PI/A HIV/AIDS is living daily not only with the medical uncertainties posed by HIV, but also with the stigma, discrimination, and prejudice, caused by fear from the rest of society about people with HIV/AIDS and their own perceived risk of infection. Given that the main goal of HBM is to predict health-related behaviour, and to frame interventions to change behaviour, the model could not be applied in this study, which sought to generate understanding about the information behaviour that people engage in after contracting life threatening and stigmatising illness. As such, the model cannot be employed to explain patterns of information behaviour of PI/A HIV/AIDS.

Theory of planned behaviour

The Theory of Planned Behaviour (TPB) is an extension of the earlier Theory of Reasoned Action (TRA) (Glanz et al., 2002; Conner and Norman, 2005; Glanz et al., 2008). It focuses on the link between attitudes and behaviour. It is a behavioural prediction social-

psychological theory that is widely applied to understand and predict the determinants of health behaviour. It asserts that the most important determinant of behaviour is the intention to perform behaviour (Redding et al., 2000; Glanz et al., 2008).

The theory was proposed by Ajzen (1991) to improve on the predictive power of the theory of reasoned action by including perceived behavioural control. It is one of the most predictive persuasion theories that have been applied to studies of the relations between beliefs, attitudes, behavioural intentions and behaviours in various fields (Conner and Sparks, 2005).

The two basic assumptions – behaviours of social relevance are under volitional control, and that people and a person's intention to perform (or not perform) the behaviour is the immediate determinant of that behaviour – underlie TPB (Redding et al., 2000; Conner and Sparks 2005; Glanz et al., 2008).

According to this theory, a person's intention to perform a specific behaviour is a function of two factors, namely: attitude (positive or negative) toward the behaviour; and the influence of the social environment (general subjective norms) on the behaviour. The attitude toward the behaviour is determined by the person's belief that a given outcome will occur if s/he performs the behaviour, and by an evaluation of the outcome.

The social or subjective norm is determined by a person's normative belief about what is important or 'significant' that others think s/he should do, and by the individual's motivation to comply with those other people's wishes or desires.

Attitudes are a function of beliefs in this theory. Thus, if a person believes that performing a given behaviour will lead to, on the whole, positive outcomes, then s/he will hold a favourable attitude toward performing that behaviour. On the other hand, a person who believes that performing the behaviour will lead to negative outcomes will hold an unfavourable attitude. These beliefs that form the foundation of a person's attitude toward the behaviour are referred to as behavioural beliefs.

Subjective norms are also a function of beliefs. However, these are beliefs of a different kind. These are the person's beliefs that certain individuals or groups think s/he should or should not perform the behaviour. If the person believes that most of these significant others think s/he should perform the behaviour, the social pressure to perform it will

increase the more s/he is motivated to comply with these others. If s/he believes that most of this reference group is opposed to performing the behaviour, her/his perception of the social pressure not to perform the behaviour will increase along with the motivation to comply with these referents (Redding et al., 2000; Conner and Sparks 2005; Glanz et al., 2008). Thus, the theory assumes that individuals behave in a certain way because they choose to do so, and use a rational decision-making process in choosing and planning their actions.

Within the field of health care, the theory of planned behaviour has been applied to study health-related behaviours, including use of illicit drugs such as cannabis, cocaine, tobacco smoking, and alcohol use. A number of sexual behaviours have been examined, including condom use in relation to the threat of HIV/AIDS and other contraceptive behaviours, casual sex and the number of sexual partners. The theories have also been applied to other risky behaviours such as the risk of riding of motorcycles, or related driving violations such as exceeding the posted speed limit in cars. It has also been applied in studies involving a range of physical activity behaviours, dietary behaviours and screening behaviours (Conner and Sparks 2005; Glanz et al., 2008). The theory states that attitudes toward behaviour, subjective norms, and perceived behavioural control, together shape an individual's behavioural intentions and behaviours. Research on TPB has been criticised on the grounds that it is more often than not focused on the prediction of behavioural intention rather than on the behaviour itself (Redding, 2000).

The theory's underlying assumption that behaviour is under volition control and people are rational beings, and as such use a rational decision-making process in choosing and planning actions meant that it could not be applied to the findings of the current study. This is simply because human beings may not always follow a rational decision-making process, particularly if they are experiencing extreme emotional stress or are under fear of social threats such as stigma and discrimination. In such situations, they may not have control of their behaviour, because human values and expectations are subjective; therefore, people's actions are not based solely on objective reality, but also on their perceptions of it. Given the main constructs of the theory, it could not be applied to the study of HIV/AIDS-related information behaviour because predicting behaviour was outside of the scope of the current study. Secondly, the participants under situations of extreme stress may not employ rational decision-making processes in choosing whether or

not to access and use HIV/AIDS-related information. The theory has mainly been used to predict behaviour based on people's intention to perform behaviour. The current study's focus was not on predicting HIV/AIDS-related information behaviour, but rather to generate the rich insights needed to understand HIV/AIDS-related information behaviour exhibited by people faced with life-threatening and stigmatising illnesses.

Social Cognitive Theory

Social Cognitive Theory (SCT) was first known as 'social learning theory' as it was based on the operation of established principles of learning within the human social context (Bandura, 1977; McAlister et al., 2008). It was renamed 'Social Cognitive Theory' when concepts from cognitive psychology were incorporated to accommodate the growing understanding of human information processing capacities and biases that influence learning from experience, observation and symbolic communication (Bandura, 1986; McAlister et al., 2008). The theory later expanded to embrace concepts from sociology and political science to advance the understanding of functioning and adaptive capacities of groups and societies (Bandura, 1997; McAlister et al., 2008). The theory has further incorporated and developed concepts from humanistic psychology by analysing processes that underlie self-determination, altruism, and moral behaviour (Bandura, 1999; McAlister et al., 2008).

SCT is a behavioural prediction theory that represents a clinical approach to health behavioural change which goes well beyond individual factors in health behaviour change to include environmental and social factors. SCT suggests that behaviour can be explained in terms of triadic reciprocity in which personal factors (one's cognitive processes), behaviour, and environmental influences continually interact in a process of reciprocal determinism (Redding et al., 2000; McAlister et al., 2008). Thus human behaviour is the product of the dynamic interplay of personal, behavioural and environmental influences. Although it recognises how these influences shape behaviour, this theory focuses on people's potential to alter and construct environments to suit purposes they devise for themselves.

The theory suggests that behaviour is a product of an individual's learning history, the present perception of the environment, and intellectual and physical capability. Therefore behaviour can be changed through new learning experiences, guidance in the adjustment of

perceptions, and support for the development of capabilities (Glanz et al., 2008; McAlister et al., 2008).

According to this theory, reinforcement contributes to learning, but reinforcement along with an individual's expectations of the consequences of behaviour determines the behaviour. Behaviour is seen as a function of the subjective value of an outcome and the subjective probability (or expectation) that a particular action will achieve that outcome. Thus people's behaviours are not always based on objective reality, but on their perception of it (McAlister et al., 2008). The theory has been widely applied to health behaviour, particularly the development of more effective cognitive-behavioural therapies, to help people change or manage unwanted behaviour and /or unhealthy life styles (Redding et al., 2000; McAlister et al., 2008).

The constructs of this model, including personal characteristics, emotional arousal, behavioural health, capacity, self-efficacy, and self-regulation, are discussed with specific emphasis on determining, prevention, and modification of unhealthy behaviour for the purposes of disease prevention, which is outside the scope of this study. This makes Social Cognitive Theory inappropriate for the present study.

The Transtheoretical Model

The Transtheoretical Model (TTM) is a dominant stage model in health psychology and health promotion that emerged from a comparative analysis of leading theories of psychotherapy and behaviour change in an effort to integrate a field that had expanded to include more than 300 theories of psychotherapy (Prochaska et al., 2008). One of the first empirical applications was to smoking cessation, whose findings revealed that behaviour change unfolds through a series of stages (Prochaska and DiClemente, 1983; Sutton, 2005). This profound insight led to the development of the TTM.

The theory was latter applied to study a wide range of health and mental health behaviours, including alcohol and substance abuse, anxiety and panic disorders, bullying, delinquency, depression, eating disorders, high-fat diets, HIV/AIDS prevention, mammography, smoking cessation, exercise adoption, sun protection, stress management, and medication adherence (Prochaska and DiClemente, 1985; Prochaska et al., 1994; Prochaska and Velicer, 1997; Redding et al., 2000; Conner and Norman, 2005; Prochaska et al., 2008).

Problem behaviours, as described by (Redding et al., 2000), are important from both a clinical and a public health stand-point because they are associated with increased morbidity, mortality and decreased quality of life. This model describes relationships between stages of change, processes of change, decisional balance, situational confidence and temptations to relapse (Redding et al., 2000).

The six stages that have been identified in the model include:

- Pre-contemplation - the person is unaware of the problem or has not thought seriously about change;
- Contemplation - the person is seriously thinking about a change (but not ready to take action immediately);
- Preparation - the person is planning to take action and is making final adjustments before changing behaviour (has a plan of action, e.g., joining a health education class);
- Action - the person implements some specific action plan to overtly modify behaviour and surroundings (e.g., total abstinence);
- Maintenance - the person continues with desirable actions (overt modifications in life style, while struggling to prevent lapses and relapse);
- Termination - the person has zero temptation and 100% self-efficacy (ability to resist relapse).

In relapse, the person reverts back to their old behaviour, which can occur during either action or maintenance. This model is a circular, rather than a linear, model. It is more of a spiral, as the person may go through several cycles of contemplation, action, and relapse (or recycle) before either reaching termination or exiting the system without becoming free of the addictive behaviour. Prochaska has used a 'revolving-door schema' to explain the sequence that people pass through in their efforts to become free from addictions. People do not go through the stages and then graduate; they can enter and exit at any point, and often recycle several times.

Although the model has been useful in providing guidelines on conducting studies on problematic health behaviours associated with increased morbidity and mortality and decreased quality of life, the context under which the model was developed, as well as its emphasis on behavioural change, including aspects such as stages of change, processes of change, decisional balance, situational confidence, and self-efficacy, and situational

temptations to lapse, makes the application of the theory to a study which sought to explore HIV/AIDS- related information behaviour inappropriate.

To summarise, the review of health behaviour models above has revealed that they were designed with a view to identifying variables that underlie health-related decisions and to assess their ability to predict health-related behaviour. Although the models have provided direction for research focusing on prediction and prevention of risky and unhealthy lifestyles, such models could be inadequate for explaining information behaviour in the context of a population that is already infected by an illness. Thus the models may not be appropriate to explain patterns of information behaviour that people engage in after contracting life-threatening and stigmatising illnesses, that is, HIV/AIDS. Thus the current study, which focuses on neither intervening with health screening nor preventive behaviour, could not apply health behaviour models to explain the lived information experiences of PI/A HIV/AIDS, including their information behaviour and the factors that shape this behaviour.

2.2.4 Health information behaviour

As a subject of scholarly attention, Health Information Behaviour (HIB) has been studied in many different contexts, with a variety of people and a broad array of motives and goals. Studies on HIB have been conducted on particular populations such as: men with prostate cancer ((Feltwell and Rees, 2004); gay men (Minion, 2010); university students (White, 2009; Sairanen and Savolainen, 2010); informal carers (Hepworth, 2004); people living in specific regions such as Canada and the USA (Veinot and Harris, 2011; Zukoski et al., 2011); and HIB in terms of cancer- related illness has also received much research attention (Johnson, 1997b; Rees and Bath, 2000; Rees and Bath, 2001b; Williamson and Manaszewicz, 2002). The amount of attention given to cancer-related information seeking research confirms Case's (2007) observation that, although everyone seeks information, only people and situations with higher stakes have a higher likelihood to attract research.

However, the same, or similar, level of interest has not been demonstrated in HIV/AIDS-related information behaviour, despite continued high rates of HIV infection globally, and in the UK in particular. Comparatively, little is known about the information behaviour of PI/A HIV/AIDS – another reason that justifies undertaking the current study in the UK. The choice of the UK context for the current study is consistent with Case (2007), who

observed that conducting research on human information behaviour in a generic way would be difficult because information behaviour takes place in a context.

In addition, studies on HIB have paid much attention to the ways information seeking contributes to participation in medical decision making, including evaluating the appropriateness of the proposed treatment, and identifying possible treatment options (Johnson, 1997b; Rees and Bath, 2001b).

Taking this view of HIB eliminates the social, psychological and economic challenges that individuals experiencing ill-health need to address in addition to making medical decisions in order to enjoy a good quality of life. The current study responds to the above concerns by exploring holistically a broad range of relevant information-related behaviours and information needs particularly in a life-threatening and stigmatising context.

Much of the current HIV/AIDS-related information research has focused on identifying HIV/AIDS-related information needs, and the sources that people access to meet their information needs. For example, a number of classifications have been made of the very varied information needs of people affected by HIV/AIDS. According to Huber and Cruz (2000), these range from drug, wellness, and financial information to information on social activities, HIV/AIDS disclosure, death and dying, and religious/spiritual topics.

Kalichman and Belcher (1997) highlighted nine domains: HIV antibody testing; sexual transmission; non-sexual transmission; ways in which HIV is not spread; disease symptoms and processes; condoms and other protective barriers; safer sex behaviours; facts about HIV/AIDS; and statistical information about the HIV/AIDS epidemic. Ko et al. (1997) classified information needs after diagnosis as relating to hospitalisation processes, physical symptoms, anti-viral drug side effects, death, insurance, planning for the future, self-care, and disclosure to others; while Zukoski et al. (2011), in a sample of 16 people living with HIV/AIDS in areas with a low prevalence of HIV/AIDS in the US, found that information was sought mainly on drug regimens, drug side effects, and drug research.

A number of studies have also investigated the array of sources and channels that people use to access HIV/AIDS-related information. These include AIDS hotlines, printed information, the Internet, television, drama, radio, songs, posters, family members, newspapers and magazines, journal articles, advice books, health fairs, local healthcare

centres, SMS, friends, celebrities, clergy and teachers. Several studies have concluded that individuals with close contact with the disease (e.g., physicians, healthcare providers and persons with AIDS) are the most trusted sources, regardless of gender, ethnicity/race, age or annual income (Marin and Marin 1990; Lagarde et al., 1998; Pennbridge et al., 1999).

Research in HIV/AIDS-related information seeking has indicated that information from local health-centres, radio and the television, had been observed to contribute to overall AIDS-related knowledge and a reduction in risk taking behaviour (Lagarde, Pison, and Enel, 1998; Marin, and Marin, 1990). However, Pennbridge et al. (1999) noted that most useful sources of health information, namely physicians and healthcare providers, are not universally seen as being easy to access.

Brashers et al. (2002a) observed that, although the study of information management in health contexts has focused on individual sources and patterns of information seeking, avoiding information is also an important element of information management. Consistent with this reasoning is (Case, 2002; Case, 2007), who noted that the study of Health Information Seeking Behaviour (HISB) has invariably become a study of information sources. The current study has responded to this concern by studying the holistic health information behaviour of PI/A HIV/AIDS, and the factors that shape this behaviour.

The role of stigma in relation to HIV/AIDS information has also been investigated because stigma is a factor which has consistently emerged as a clear barrier to information seeking and access in a number of studies. Ko et al. (1997), for example, in an intensive study entailing continuous contacts over four months with a recently-diagnosed, HIV positive gay man, found that stigma was an obstacle to information seeking. They noted the importance of non-judgmental attitudes in reducing the effects of stigma as a barrier to information seeking. Magee et al. (2011), in a mixed methods study of 32 lesbian, gay, bisexual and transgender (LGBT) young people (aged 16-24), found that while fear of becoming infected with sexually transmitted diseases and HIV was a driver for engaging in information seeking, a reason cited for not searching was not wishing to be observed doing so due to stigma. Zukoskia et al. (2011) also found, in a qualitative study of 16 people living with HIV/AIDS in areas with a low prevalence of HIV/AIDS in the US, that those problems which inhibited accessing information included 'stigma, fear, concern about disclosure, and feelings of futility and anger'. Veinot's (2009) study with 34 persons infected with HIV, 28 of their friends and/or family members living in three rural areas in

Canada, and 52 healthcare and information providers, indicated that, although HIV/AIDS-related information is a vital resource for PI/A HIV/AIDS, they concluded that fear of stigma was an inhibiting factor resulting in people's avoidance of information seeking, as well as a preference for information from health professionals bound by professional codes of practice. Such fears may lead to privacy being a prime concern in the information seeking of people living with HIV/AIDS, and this subject has been researched in a recent study by Mazanderan and Brown (2001) who explored, via qualitative interviews, the health information seeking of 41 women living with HIV. The aims were to use the case of how people living with a chronic stigmatized illness go about seeking health information to develop a relational and spatial understanding of privacy.

The effects of stigma, particularly if privacy issues are not addressed, may lead to the need for people living with HIV/AIDS to engage in the management of silence. This theme emerged in a study by Fielden et al. (2011) which entailed conducting interviews with adolescent service providers from Australia, Canada, the UK and the USA. The authors suggested that HIV is a disease that combines stigma elements of perceived contagion and socially undesirable behaviours. They pointed out that managing this stigma entails managing silence in the context of the social worlds of the young person, the family and the service provider. Silence emerged as a key theme in the participant narratives and was embedded in the descriptions of young people's lived experiences. Crucially, silence is a product of oppression and inequity but is also a tool for resistance. Silence defends secrets and exists in the spaces, both physical and social, that are created for them in order to manage the stigma in young people's lives.

While stigma can hinder information seeking, information seeking in turn has been positively linked to adherence to treatment regimes. Samal et al. (2011), for example, conducted a survey of 433 people infected with HIV at four HIV outpatient clinic sites in the United States, 334 of whom were on antiretroviral therapy (ART). They found that higher levels of health information seeking were linked to adherence to ART, after controlling for age, gender, race, education, clinic site, and medication self-efficacy. Stigma itself has been linked to poor adherence to treatment and access to medical care. Sayles, Wong, Kinsler, Martins and Cunningham (2009), for example, in a study of 202 people living with HIV/AIDS in the US, found that HIV stigma was associated with poor

adherence to antiretroviral therapy and access to medical care. They called for research designed to better understand the effects of stigma and how it may be mediated.

Non-adherence to therapy can also be affected by misleading information sources. Samal et al. (2011), for example, in a US-based study of internet health information seeking amongst HIV-infected patients at four HIV outpatient clinic sites, suggested that while the Internet has the potential to educate persons living with HIV/AIDS (PLWHA), websites may contain inaccurate information and increase the risk of no adherence with antiretroviral therapy (ART). Misleading information was reported to be encountered more frequently from social networks than specialised sources in the previously mentioned study by Veinot et al. (2006). However, social networks have been identified in other studies as particularly important sources of information for people affected by HIV/AIDS. For example Harris, Veinot and Bella's (2010) study of how HIV/AIDS information and support were exchanged by people infected by HIV/AIDS and their formal and informal caregivers, in three rural regions of Canada, illustrates the power of access to timely support from trusted members of the social networks.

In a survey of the patterns, and potential predictors of the information behaviour of 162 HIV positive gay men living in San Francisco by Lovejoy, Morgenroth, Paul, Freeman and Christianson (1992), most of the sample had developed multifaceted information networks within a year of being diagnosed. The amount of help obtained from these networks, and the frequency of consultation, was positively linked to HIV self-care patterns and 'feeling calm'.

A number of studies have also focused on factors associated with differing levels of information seeking. In the previously mentioned study by Samal et al. (2011), higher levels of health information seeking were associated with younger people, those with a higher level of educational achievement, and those with higher medication self-efficacy. White (2009), in a mixed methods study based on a survey of 628 students and follow-up interviews with 24, investigated HIV/AIDS-related information seeking among university students in three Caribbean countries. He found that HIV information seeking was significantly associated with health consciousness and direct experience of HIV/AIDS. It was not associated with self-efficacy or risk perception. Qualitative data revealed that low risk perception and high self-efficacy beliefs resulted in participants feeling that they had no need to seek HIV/AIDS-related information.

Unlike previous work above that focused on particular aspects such as sources of information within an HIV/AIDS-related information context, the current study sought to generate an holistic view of this context, including the challenges, dilemmas, and frustrations that people experience in accessing and using HIV/AIDS-related information, and the patterns of information behaviour people adopt within this context. The current study sets out to address a gap identified by Albright and Kawooya (2007) who suggested the need to conduct studies that investigate the situations of people infected with or affected by HIV/AIDS and dig deeper into the underlying individual complexities in an HIV/AIDS information context in order to identify patterns of HIV/AIDS related information seeking and use.

The review of literature on the theoretical underpinnings of Health Information Behaviour (HIB) identified Johnson and Meischke's (1993) comprehensive model of cancer-related information seeking applied to magazines; Longo's (2005) expanded model of health information seeking behaviours; and Freimuth et al.'s (1989) health acquisition model. A brief review of each of the models is given below.

Freimuth's (1989) model of health information and acquisition

Freimuth et al.'s (1989) health information and acquisition model was developed based on data generated during their evaluation research of cancer information services in 1975. The model is limited to information acquisition only. It provides a series of six steps that are depicted as a decision-making flow-chart, in which a decision at one point determines if one moves forward to the next step or repeats a previous step. The strength of this model is that it acknowledged that information seeking can be iterative by providing a feedback loop. The model does not take into account the role that psycho-social, environmental and other contextual factors may play in influencing information acquisition. Although the model may be used, to a limited extent, to explain the information acquisition processes of PI/A HIV/AIDS, the fact that it is confined to information acquisition makes it inadequate for a study that seeks to generate much fuller and more holistic view of health information behaviour.

Longo's (2005) comprehensive model of health information seeking

Longo's (2005) comprehensive model of health information seeking was developed based on a research agenda and empirical data provided by pilot studies in the area of breast cancer; it was later expanded based on deliberations with experts for other clinical conditions, such as arthritis and diabetes. The model presents a number of personal and contextual factors which lead to phases of information use that can be either passive or active. The model ends with particular outcomes for the individual. However, the model does not add to our understanding of complex health information behaviour because, apart from actively or passively seeking information, no other pattern of HIB is depicted by the model. Although the model is developed based on women who had previously been diagnosed with cancer, it makes no attempt to explain the effects of emotional distress on information behaviour. It is surprising that stress could be excluded from consideration in the lives of people experiencing a life-threatening and debilitating condition like cancer. Although the model is based on empirical research, no empirical evidence is given to support the claims.

Johnson's (1997b) comprehensive model of information seeking

Johnson's (1997b) comprehensive model of information seeking was developed from data that were generated in a study that investigated purposive acquisition of information from magazines on mammography screening. The model suggests that four sets of antecedents, namely: demographics, direct experience, beliefs, and salience, motivate the drive for information seeking actions, which are shaped by information carrier factors (Johnson and Meischke, 1993). The first two are grouped as background factors. One of the factors is demographics. It includes age, gender, and ethnicity, along with socio-economic variables such as education, occupation and wealth status. Historically, demographics have been a focal point for social research which seeks to find patterns among the behaviours, beliefs, and attitudes of populations, based on correlations with such demographic variables. Although demographic factors have been used to predict information use, for example in health contexts, other variables were found to account for low levels of information seeking (Lenz, 1984; Johnson and Meischke, 1993; Case, 2007). Consistent with this reasoning is Case (2002), who pointed out that the context or situation in which information seeking takes place, is a much more powerful predictor of thoughts and behaviour than demographic

factors are. Direct experience was another important background factor that was reported to affect information seeking (Johnson and Meischke, 1993; Johnson, 1997b). It includes an individual's personal level of experience with the health condition, which may relate to a person's social network. That is, who do I know that might know the answer to my question? Or, who knows how to find out?

The third and fourth factors, also referred to as personal relevance factors, include beliefs about outcomes of information seeking, and the salience of information. Johnson (1997b) pointed out that information seeking is related to the extent to which individuals perceive they control the future, or perceive there are efficacious methods of control. On the other hand, salience of information implies that information is not only relevant to the need, but is applicable (Johnson, 1997b).

The second section of Johnson's (1997b) model consists of information carrier characteristics. He points out that people are interested in the content of the information, and not the channel through which it arrives. According to Johnson (1997b), use of channels tends to be predicted by the social presence, the extent to which they reveal the presence of human interactions, and also whether they can capture the human side of relationships. The last component of Johnson's model is information seeking actions. He observed serious difficulties in studying the distinctions people make when looking for information; e.g., active or passive information acquisition. Consistent with this reasoning is White (2009), who observed that we ought to be concerned with whether information was actually obtained, rather focusing on distinguishing between how information was sought: actively or passively.

Johnson's (1997b) model fits the data of his study, but it is limited as it is only based on purposive seeking of breast cancer-related information from magazines. It is uncommon for individuals to seek information from only one source. Johnson's (1997b) model has the desirable quality of simplicity, because it moves in a chainlike sequence in one direction; however, it has been criticised on the grounds that it lumps together all the antecedent factors, emphasises source characteristics, and makes no attempt to spell out the various forms of actions people might take (Case, 2007).

The model that was developed based on a study of a general population of women not affected by cancer is useful in predicting information seeking about cancer; however, it

may be inadequate in explaining information seeking activities of people diagnosed with cancer, as the information behaviour of these two groups of people could be entirely different. For example, people undergoing chemotherapy or experiencing extreme effects of cancer, may undergo emotional distress which could greatly influence the forms of actions towards seeking information in a number of different ways. This observation suggests the need for models of information behaviour to not only account for the information behaviour of people who interact with information to prevent illness, but also for groups of people who experience extreme distress and, in some cases, stigma, because of their illness.

2.2.4.1 STIGMA, COPING AND HEALTH-RELATED INFORMATION BEHAVIOUR

Health information seeking is a relatively new phenomenon; however, widespread availability of information, and the tendency for individuals to be involved in accessing and using information beyond medical professionals, has attracted the interest of researchers into this phenomenon (Dutta-Bergman, 2005). Health related information behaviour, particularly information seeking has been acknowledged as a mechanism for coping with health-related events (Lenz, 1984; Lambert and Loiselle, 2007).

Lambert and Loiselle (2007) who conducted a literature review on approximately 100 published articles and five books reporting HIB from 1982 to 2006, identified 11 varying definitions of the term, and concluded that there is no dominant explicit definition for HIB. They attributed lack of an explicit definition to the widespread use of the term in disciplines such as medical sciences, public health, health education, library and information science and health communication, all of which hold distinct perspectives. In the most general sense, HIB relates to ways in which individuals go about obtaining information, particularly, information related to their health (Lambert and Loiselle, 2007; White, 2009).

Lambert and Loiselle (2007) observed that the precise phrase ‘health information seeking behaviour’ has not appeared consistently in the literature. Variations of this term include: ‘information seeking’; ‘health information seeking’; ‘information seeking behaviour’; or ‘health information seeking behaviour’. They suggest that consistent use of the phrase ‘health information seeking behaviour’ could separate the concept of HIB from a larger body of literature on information seeking, which relates to accessing information in several

other contexts outside health. However, researchers such as Case (2005), White (2009), Veinot (2009), and Narayan et al. (2011), have indicated that, in a health context, individuals may opt to avoid information.

Research on processes related to HIB is becoming increasingly central in generating insights into ways in which individuals cope with health threatening situations (Johnson and Meischke, 1993; Johnson, 1997b; Case et al., 2005; Dubois and Loiselle, 2009; Veinot, 2009; White, 2009; Sairanen and Savolainen, 2010).

Some researchers, such as Lambert and Loiselle (2007), described health information seeking as a problem-focused strategy where individuals focus their attention on the threatening situation, and direct their efforts to becoming more in control. Research has been conducted on the type of information individuals seek to cope with stressful situations, the amount of information sought, how the information is obtained, and when or under what circumstances the information is needed (Miller, 1991; Kalichman and Belcher 1997; Rees and Bath, 2000; Rees and Bath, 2001a; Lambert et al., 2009; Veinot, 2009). Consistent with this reasoning is Lazarus and Folkman's (1984) stress, appraisal and coping theory where HIB is typically referred to as a problem-focused coping strategy. This implies that individuals focus their attention on the threatening situation and direct their efforts at mitigating the effects of the stressors (Lambert and Loiselle, 2007). Information seeking in health contexts is reported to enhance coping because of its potential to help individuals understand the health threat and the associated challenges that it brings, increase predictability and feelings of control over situations, and support informed decision making (Lambert and Loiselle, 2007). Although individuals may choose to cope with a health-related threat by seeking information, others may purposefully avoid such information (Feltwell and Rees, 2004; Case et al., 2005; Lambert and Loiselle, 2007; Sweeny et al., 2010; Narayan et al., 2011). This following section discusses Lazarus and Folkman's (1984) Stress, appraisal and coping theory and Goffman's (1963) Stigma management theory, that have been applied in studies exploring stigma and stress-related contexts.

Stress, appraisal and coping theory

Coping has been defined as constantly changing cognitive and behavioural efforts to manage specific internal and/or external demands that are appraised as taxing and

exceeding the resources of the person (Lazarus and Folkman, 1984). Lazarus and Folkman's (1984) definition is appropriate for the current study because it is concerned with anything that a person does, or thinks, in a particular context, regardless of how well or badly it works, and avoids equating coping with mastery. Hence, coping is not about mastery over the environment, but rather it allows the person to tolerate, master, minimise, accept or ignore what cannot be mastered.

This theory asserts that the main coping strategies are emotion- and problem- focused coping strategies (Lazarus and Folkman, 1984). Thus, coping could be directed at managing or altering the problem causing the distress, also known as problem-focused coping; and/or regulating emotional responses to the problem, also known as emotion-focused coping (Lazarus and Folkman, 1984; Lazarus, 1993). Emotion-focused coping strategies consist of cognitive processes directed at regulating emotional distress. The most common strategies include avoidance, minimisation, distancing, selective attention, positive comparison and wresting positive value from negative events (Lazarus and Folkman, 1984; Lazarus, 1991; Lazarus, 1993). Emotion-focused coping strategies mainly occur when individuals make an appraisal that nothing can be done to modify harmful, threatening or challenging environmental conditions (Lazarus, 1993). Thus emotion-focused strategies are employed to maintain hope and optimism, to deny the implications of facts, to refuse to acknowledge the worst, and to act as if what happened did not matter.

Key components of stress theory are an appraisal by an individual of the significance of a situation and coping; i.e., their attempt to manage associated demands on them. Stress may be experienced insofar as a situation perceived as significant to the individual has associated demands which 'tax or exceed available coping resources' (Lazarus and Folkman, 1986). Coping strategies may be problem-focused (attempting to change the situation) or emotion-focused (attempting to change the appraisal). Lazarus (1991) elaborates nine negative emotions (i.e., anger, fear, shame, guilt, sadness, envy, jealousy, disgust and anxiety) and four positive emotions (i.e., happiness, relief, pride and love).

Studies of coping with HIV/AIDS, such as those of Fleishman and Fogel (1994) and McCain and Gramling (1992), have indicated that persons infected with HIV/AIDS employ various social and psychological strategies to cope with HIV/AIDS-related stress. According to Lazarus and Folkman (1984), stress is a relationship between the person and

the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her wellbeing.

Some of the studies that have employed a similar framework include: Peterson et al.'s (1996) study looking at coping with HIV, psychological resources, and the depressive mood in African-American gay, bisexual and heterosexual men; Fleishman and Fogel's (1994) study of coping and depressive symptoms among young people with AIDS; and Rees' (1999) study that focused on identifying information needs and the information seeking behaviour of women with breast cancer.

Stigma management theory

Goffman (1963) defined stigma as a deeply discrediting attribute in the context of normative expectations about a person's identity. In Goffman's (1963) view, possession of a socially stigmatised attribute causes a person to be viewed as less than fully human. He observed that, based on the assumption that the person with stigma is not human, people discriminate in a variety of ways. They may construct a stigma theory to explain the inferiority of the stigmatised person and account for the danger s/he represents, and the animosity s/he experiences. This leaves a stigmatised person with a 'spoiled' social identity, which isolates that person from both society and from him- or herself. Goffman (1963) suggested that, among other attributes, people may be stigmatised on the basis of their perceived conduct. In addition, Goffman (1963) postulates that intentional and explicit stigmatisation tends to be directed at people who are stigmatised on grounds such as homosexuality, suicidal tendencies, alcoholism, addictions and mental illness.

Scholars such as Herek (2002), Herek and Capitanio (1999), and Fife and Wright (2000), have argued that HIV/AIDS-related stigmatisation can be viewed as a 'conduct stigma'. This is because HIV infection is seen to be the result of voluntary, avoidable behaviours that are 'morally questionable', such as drug use, homosexuality or sexual promiscuity. Consequently, rather than empathy or sympathy, persons infected with HIV/AIDS, as well as their immediate family, may be subject to an angry, moralising blame for their illness (Herek and Capitanio, 1999; Helman, 2001; Herek, 2002).

Goffman (1963) argued that when a person's stigmatised identity is not immediately known in a social interaction, s/he may be able to 'pass' as 'normal'. Previous research has

also shown that many persons infected with HIV (PI/HIV/AIDS) choose not to disclose their HIV status, or to do so selectively, as a result of stigmatisation (Kalichman et al., 2003; Medley et al., 2009). Goffman (1963) pointed out that 'passing' involves the use of techniques of information control, including making choices about when to display or not to display, to tell or not to tell, to lie or not to lie; and in each case, to whom, how, when and where.

Goffman (1963) argued that people experiencing stigma are likely to talk about their stigmatising experiences with people who share their stigma, who he terms 'the own'; as well as 'the wise', people whose 'special situation' makes them knowledgeable of, and sympathetic to, the experiences of stigmatised people. For instance, in the case of an illness, healthcare providers may be among 'the wise'. He also argued that people close to stigmatised people may themselves be stigmatised, a phenomenon which he termed 'courtesy stigma'. A number of studies cited HIV/AIDS-related stigma, including moral judgement and rejection, as a major barrier to the uptake of HIV testing and counselling, seeking medical attention and seeking information (Medley et al., 2009; Zhou, 2009; Tiffany, 2010; Zukoski et al., 2011).

Informational coping strategies of avoidance

Case (2005) observed that many previous studies have assumed that people seek or pay attention to sources of information, which explains the focus on the benefits of acquiring information, and give inadequate attention to the information behaviour of people who may choose not to know. Brashers et al.'s (2002a) observation that research on information management has predominantly focused on individual's sources and patterns of information seeking, despite the importance of information avoidance in information management, confirms Case's (2005) observation.

Nevertheless, the review of the current study has identified recent studies on information avoidance. The work of researchers such as Brashers et al (2002a) on information seeking and avoiding in health contexts; Sairanen and Savolainen (2010) on avoiding health information in the context of uncertainty management; Case (2005) on avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts; Barbour et al.'s (2012) work on avoiding health information; and Sweeny et al.'s (2010) work on information avoidance – who, what,

when, and why – have generated rich insights into motivations that lead to information avoidance, the forms that avoidance may take, and the conditions under which information avoidance is most likely to occur.

Sweeny et al. (2010) defined information avoidance as any behaviour intended to prevent or delay the acquisition of available but potentially unwanted information. Information may be avoided intentionally, as in the case of people who are ill, or believed to be at risk of contracting a disease, especially if receiving information can lead to distress (Brashers et al., 2002a). Information may also be avoided if seeking information has intolerable personal risks or costs (Veinot, 2009). Such avoidance may focus on individual information sources, or specific information content available in the source. Information may also be avoided by intentionally abstaining from thinking about an issue of concern, or just physically living the situation (Brashers et al., 2002b; Case, 2007; Sweeny et al., 2010).

Information avoidance has been the subject of research for many years (e.g., Frey, 1982). It also continues to be a focus of current research; for example (Sweeny et al., 2010; Narayan et al., 2011), and is particularly relevant to health information (Barbour, Rintamaki, Ramsey, and Brashers, 2012; Case, Andrews, Johnson, and Allard, 2005). As noted by Narayan et al. (2011):

Information avoidance strategies in the area of diet and consumer health for example, can include behavioural disconnection [It's bad for me, but I eat it anyway], denial [“It's not as bad as they say”], fatalism [“We're doomed anyway”], cognitive repression [“I don't think about it”], and magic thought [“My body can handle it”].

Information avoidance has been studied particularly intensively in the field of health information. Barbour et al. (2012), for example, note that participants in their study of 507 students and 418 community members reported that they avoided health information in order to:

“(a) maintain hope or deniability; (b) resist overexposure; (c) accept limits of action; (d) manage flawed information; (e) maintain boundaries; and (f) continue with life/activities”.

They also reported strategies for avoiding information, including removing or ignoring stimuli (e.g., avoiding people who might provide health advice), and controlling conversations (e.g., withholding information, changing the subject).

Case et al. (2005) demonstrated that the notion of avoiding health-related information has a long history in psychology and communication studies. At the beginning of the 1900s, Freud's theories about psychological defences (repression, suppression, and denial) shed light on psychic mechanisms that people employ to ignore uncomfortable thoughts. In the 1940s, when communication scientists became interested in factors explaining the failure of health promotion campaigns, people's selective exposure to information appeared to be a dominant factor (Case et al., 2005). According to Hyman and Sheatsley(1947), humans tend to seek information that is congruent with their prior knowledge, beliefs, and opinions, and to avoid exposure to health information that conflicts with those internal states.

The questions of health information avoidance have also been approached from the viewpoint of 'fear appeals'. For example, Janis and Freshback's (1953) study suggested that extreme attempts to frighten people into practicing good dental hygiene, by showing them pictures of mouth cancer and deformed teeth, were not very effective as they lead people to ignore the threat, particularly if it is perceived as extreme, or if any potential responses are not expected to be effective.

Other studies have also reported the experience of the effects of information overload. Hogan and Palmer (2005), for example, investigated the information behaviour of people living with HIV/AIDS in the US, via a nationwide survey distributed at clinics, drug treatment centres and AIDS service organisations. 72% of their sample reported actively searching for HIV/AIDS-related information. However, 71% agreed that it is easy to feel overwhelmed by information, and 31% agreed that not seeking information can be beneficial. The avoidance of health information reminds us that individuals may not be willing to access and use information on their health, especially in instances when receiving information could result in emotional distress.

Informational coping strategies of monitoring and blunting

Since the 1960s, psychologists have explored information avoidance as a trait in the context of coping behaviour and stress management. Authors such as Miller (1987, 1991), who investigated experimentally how individuals expose themselves to stressful situations; i.e., in which there was a threat to one's life; introduced two related terms, 'blunting' and 'monitoring' in relation to information seeking styles. They postulated that 'monitors' actively scan the environment for threats; whereas 'blunters' tend to avoid threatening information, or distract themselves from it. Lambert and Loiselle (2007) have criticised Miller (1991) on the grounds that categorising individuals as 'monitors' and 'blunters' does not optimally capture differential patterns of HISB.

In view of the above criticism, Lambert et al. (2009) identified some characteristics of blunting, including: minimal information seeking, where individuals exhibit limited interest for cancer information; and guarded information seeking, which is characterised by juggling between the interest for selectively seeking cancer information and apprehension of coming across undesirable information of this kind. However, in guarded information seeking, 'not knowing is better' was the main thought expressed toward cancer information. The 'not knowing is better' approach was often motivated by the great anxiety felt after the cancer diagnosis therefore the participants wanted to control their emotions by shunning additional cancer information.

2.2.4.2 SUMMARY

The interdisciplinary nature of the current study warranted a review of models within health psychology and information science with a view to identifying a theory that could explain HIV/AIDS-related information behaviour. Although the review is not exhaustive, well-known and widely applied health behaviour and information seeking behaviour models and theories were reviewed in order to provide a strong theoretical background for the proposed model of HIV/AIDS-related information behaviour.

A review of the most commonly-used health behaviour models in Section 2.2.3, has shown that these models were employed in the public health arena to predict who would utilise screening tests and /or vaccinations (Rosenstock, 1966; Becker, 1974; Redding et al., 2000). The review has indicated that Health behaviour models have been applied in

the prediction of a broad range of health behaviour such as preventive health behaviour; diet and exercise, health risk behaviour; weight loss, smoking, alcohol abuse and HIV risk behaviour: compliance to recommended medical regimens. However, given that health behaviour models' goal is mainly prediction of health behaviours, they could not be applied to explain the findings of this study, which sought to generate understanding about the information behaviour that people engage in after contracting a life threatening and stigmatising illness.

Health behaviour models fundamentally provide direction for research in the prediction of health related behaviour. As such, they are useful in explaining behaviour in relation to prevention of risky and unhealthy lifestyles. However, such models could be inadequate in explaining behaviour for a population that is already diagnosed with a health condition. Thus, they could not be employed to explain patterns of information behaviour that people engage in after contracting life threatening illnesses such as HIV/AIDS. Therefore, the current study which neither focuses on intervening with health screening, nor on preventive behaviour, cannot apply health behaviour models to explain lived information experiences of PI/A HIV/AIDS, including their information behaviour and the factors that shape this behaviour. The inadequacy of such health belief models generated a need to review models of information seeking and information behaviour.

A review of information behaviour models in Section 2.2.1, has shown that most of the models were developed in contexts which focused on information seeking behaviour undertaken by people in work-related and/or academic contexts where individuals come to an information system with a defined information need, look for information, find information and solve their problems. For example, Wilson's models do not identify any other forms of information behaviour apart from information seeking. Wilson (1999) also alludes to the fact that failure only occurs when information cannot be found or when information cannot be used. The current study suggests that social dimensions such as fear of stigma, prejudice and discrimination in the face of a stigmatising illness, and emotional distress due to one's own reactions to the diagnosis, could result in a wide range of patterns of information behaviour other than information seeking. Thus the current study moves to deeper levels with finer details of the complexities of human information behaviour.

Wilson's (1999) acknowledgment that his model only provides a map of the area, identifying research gaps and suggesting no causative factors in information behaviour, is

another justification for developing a model that puts into consideration the challenges, dilemmas and frustrations people face in accessing and using information. For example, no attempts are made to explicitly explain the role of intervening variables such as source characteristics, or psychological and environmental factors, in shaping information behaviour.

The models such as Krikelas's (1983), Wilson's (1999), Leckie et al.'s (1996), Foster's (2004), Kuhlthau's (1993b) and Ellis's (1998) are predominantly library search models, with special emphasis on rational information seeking efforts of professionals and researchers. Although Krikela's model could be applied to ordinary life, nevertheless it is inclined to the rational library-based search processes of information seeking of students or professionals within work-related contexts. The models pay inadequate attention to other forms of information behaviour, such as hiding, destroying, avoiding, and sharing, as well as covert and hysterical information seeking as identified in the current study.

Just like Wilson's (1999) model, Krikelas's (1983) model also pays inadequate attention to factors that shape information behaviour. It assumes that work-related roles and the need to keep up with literature relevant to one's role stimulate information gathering and giving. For example, Krikelas (1983) describes preference for sources but no attempt is made to illustrate the relationship between the nature of information sources and information behaviour.

Like Krikelas (1983), Leckie et al.'s (1996) model is restricted to a range of professionals such as doctors, lawyers and engineers. The model is restricted to information seeking and pays inadequate attention to the role of the nature of information, mental and emotional states, or the perception of other people's attitudes and reactions in shaping information behaviour. The diagram by Leckie et al. (1996) has limited applicability to everyday-life information seeking because it is clearly characteristic of work-related information seeking processes.

Savolaines's (1995) Everyday Life Information Seeking model offers a shift of attention from work-related processes to the study of everyday life. However, this model cannot be used to explain the information behaviour of PI/A HIV/AIDS because it was developed based on a study of the information seeking of teachers and workers in relation to hobbies and shopping. The context of the people studied is relaxed, not warranting pessimism

compared to that of the people studied in the present research. Although Savolaines's (1995) observation that life-style and social class affect information practices could be valid for people seeking information in normal and less stressful everyday-life endeavours, this observation is not necessarily true for people seeking information in stigmatising, marginalising and life-threatening contexts such as being affected by, or infected with, HIV/AIDS.

The model does not attempt to discuss other forms of information behaviour such as hiding, sharing, and avoiding information as characteristic of everyday living. The model does not show whether people's emotional state or the nature of information could influence information behaviour. Arguably, Savolaines's (1995) model does not reflect the complexities, subtleties, and dilemmas associated with accessing and using information in everyday life, in stigmatised, depressing and traumatising contexts.

Dervin's (1986) Sense Making model is useful insofar as it increases understanding of the importance of sense making in motivating information seeking. Although the model increases our understanding about the need to make sense of the unruly and problematic world, through seeking information to bridge the gap, it does not pay attention to the challenges, dilemmas, frustrations and disconnects people may face in trying to close the gap. The model does not illustrate how such complexities could influence efforts to access and use information to close the gap.

While seeking information could be one of the options selected to close the gap, it could potentially enlarge the gap. For example, seeking information about the side-effects of taking HIV medications could stimulate anxiety and stress. In such instances, as evidenced in this study, a person may opt to reduce the gap by avoiding receiving more such information. The current study has added to the body of research by demonstrating that sense making could entail employing other information behaviour options, such as avoiding, sharing, ignoring or hiding information to close the gap.

The model also assumes that people are always in a position to make sense of a situation. However, some of the time people may be happy not to make sense of the situation, especially when engaging in information seeking is perceived to be costly and risky. For example, when people anticipated that seeking HIV/AIDS-related information could result in emotional and physical risks such as abuse, stigma and discrimination, they opted to

avoid information, seek information clandestinely, or even destroy information. The above discussion emphasises the need to conceive information behaviour as all endeavours to engage or not engage with information as people construct their life.

Dervin's (1980) study found that patients' information seeking and use was predicted by their descriptions of their situations; it did not attempt to explain how people navigate the gap within health-related life-threatening contexts. The model is also criticised for not capturing the fundamental features within the person and in the environment that trigger information behaviour. For example, Savolainen (1995) observed that although the focus of Dervin's (1986) Sense Making theory on the individual sense maker is useful, it is confined to information seeking and is too generic.

Godblod's (2006) models – an extension of Wilson's models of information behaviour and Dervin's 1999 model of sense making – extended existing research by depicting a multi-directional process through Dervin's gap and including other forms of information behaviour, such as hiding, avoiding, and destroying information, beyond information seeking alone. Although Godblod's (2006) models incorporate multi-directionality and identify ways in which an individual may navigate the gap using modes of information behaviour beyond information seeking, the models do not attempt to explicitly provide empirical evidence as well as theoretical explanations for the forms of information behaviour identified.

Godbold (2006) is criticised for not explicitly discussing the intervening variables including the personal and environmental challenges (such as the nature of information resources, social stigma, and mental and emotional state) which influence the information behaviours that people adopt in navigating the gap.

Foster's (2004) non-linear model of information seeking behaviour, which was developed based on a sample of interdisciplinary researchers, is valid in explaining the information behaviour of this particular group because it illuminated possible routes researchers could take, such as opening, orientation and consolidation, in finding information on a topic. Foster also described the cognitive approach, and internal and external contexts as important components in the interdisciplinary researcher's information seeking endeavours.

Although the model is valid in as far as portraying information seeking as a non-linear process within an academic context, it could not be applied to the current study due to the following reasons. The model is confined to information seeking and does not reflect the many other ways people and information interact. The complex information experiences, including information behaviour, of persons infected with HIV cannot be explained by a model developed in an academic context because their aim of engaging in information behaviour is different. Researchers want to find information about a topic, while PI/A HIV/AIDS want to find life-saving information. Unlike researchers, PI/A HIV/AIDS need to deal with emotional distress, and calculate the cost of engaging in information behaviour before starting, and during, the information behaviour journey. Just as Bates (2010) observed, the current study proposes developing a rich, detailed and nuanced model, that suggests ways in which information behaviour might be shaped.

Models such as Kuhlthau's (1993b) Information Search Process, Krikelas' (1983) Information Seeking Model, and Ellis' (1998) Information Seeking Characteristics, although invaluable in understanding scholarly information seeking, have been criticised for portraying the information seekers' actions in a sequential fashion (they are predominantly similar to conventional flow-charts) (Godbold, 2006; Case, 2007; Johnson, 2009). By offering rational approaches to problems which sometimes may contain irrational elements, the models jeopardise their practical application since people do not necessarily apply sequential, orderly, mechanistic, approaches to problem solving. For example, the current study has shown that information behaviour in the face of a life threatening illness: HIV is an on-going undertaking where people employ different forms of information behaviour such as seeking, hiding, avoiding, destroying or sharing information, depending on their emotional state, resource availability, or constraints and social costs of information behaviour.

The review has revealed a number of shortfalls in many existing models, including being confined to information seeking, assuming sequential procedures in the information process, paying little attention to the challenges, dilemmas and disconnects experienced by people in the course of accessing and using information, and assuming that people can always make sense of their situation and use information to close the gap. The inadequacy of such information behaviour models generated the need to review models and theories of health information behaviour.

The review of models and theories applied to health information behaviour in Section 2.2.3.1, revealed that most of these models were developed in contexts related to cancer-information acquisition or seeking. For example, Freimuth's (1989) model of health information and acquisition provides a series of six steps that are depicted as a decision making flow-chart where a decision at one point determines if one moves forward to the next step or repeats a previous step. However, since the model was developed based on a study population of people faced with a life-threatening condition that does not attract moral blame, stigma and discrimination like HIV/AIDS, the information experiences of these two groups of people are extremely different. For example, the model did not take into account the effect of incriminating, sexist, or racist over-tones on information behaviour.

Similarly, Longo's (2005) comprehensive model of health information seeking was developed based on women seeking breast cancer information, and generated a useful understanding about the number of personal and contextual factors that lead to phases of information use that can either be active or passive. Inclusion of outcomes is a very strong feature of the model; however, the model does not substantially add to our understanding of the complexities of health information behaviour, particularly in life threatening and stigmatising contexts.

Johnson's (1997b) comprehensive model of information seeking was developed out of data that was generated in a study that investigated purposive acquisition of information from magazines on mammography screening. Johnson's (1997b) model fits the data of his study; however, it is limited, as it is only based on purposive seeking of breast cancer-related information from magazines. It is uncommon for individuals to seek information from only one source. The model that was developed based on a study of a general population of women not diagnosed with cancer is useful in predicting information seeking about cancer; however, it may be inadequate in explaining information seeking activities of people diagnosed with cancer, as the information behaviour of these two groups of people could be entirely different. For example, people undergoing chemotherapy or experiencing extreme effects of cancer may experience emotional distress which could greatly influence the forms of actions towards information in a number of different ways. This observation suggests the need for models of information behaviour to not only account for the information behaviour of people who interact with information to prevent illness, but also

for groups of people who experience extreme distress, and in some cases stigma because of they have been diagnosed with a chronic illness.

From the review of the health behaviour models, information behaviour, and health information seeking models and theories, a wide range of factors to explain information acquisition have been identified. What is totally unclear are the patterns of information behaviour, the theoretical explanation of these behaviours, and the factors that shape information behaviour in life-threatening, stigmatising contexts.

The current study seeks to extend the existing body of research by applying Lazarus and Folkman's (1984) stress appraisal and coping theory, and Goffman's (1963) stigma management theory, to explicitly explain why people faced with a life-threatening and stigmatising condition such as HIV/AIDS, could adopt the different modes of information behaviour identified by this study.

The current study suggests the development of a model which not only describes the forms of information behaviour within stigmatising and life threatening contexts but also explains why such behaviours could be adopted, and also considers how this understanding could potentially be used to predict information behaviour in such contexts. However, the predictive ability of this model would require testing in a large-scale longitudinal quantitative study.

The specific aim is to move beyond relatively reductionist and simplistic representations of information behaviour by developing a model that addresses the finer details of the complexities of human information behaviour, particularly in life-threatening and stigmatising health-related information interactions. This could potentially illuminate ways in which information services could be responsive to the needs of PI/A HIV/AIDS, and provide a basis for proposing recommendations for information management in health contexts. Thus, in addition to paying attention to how and when people relate to information, the model highlights challenges and dilemmas experienced by people faced by the life-threatening and stigmatising illness of HIV/AIDS, in order to generate rich insights about the patterns of information behaviours identified in this group of information users.

2.3. Conclusions

Overall, this review has indicated that a common denominator of the health behaviour models is predicting health behaviour; while that of the information seeking and information behaviour models is description of the information seeking process.

A growing body of research exists on how information can support PI/A HIV/AIDS, mainly in the USA, Canada and Uganda. Previous research has shown that information may be required on medical and medication-related issues, financial matters, disease transmission and methods of protection. People may obtain this information from a variety of resources, including inter-personal and mass-media sources; although the most trusted sources are often people who have close contact with the disease, e.g., healthcare professionals (HCPs), and other people with the condition, although HCPs are not always easy to access. Cultural, economic and resource-related barriers prevent people from obtaining information; however, the stigma associated with the disease is a particularly important barrier. People may avoid information for a variety of reasons and different factors may affect people's information behaviour. However, there is still much to learn regarding PI/A HIV/AIDS's information behaviour; for example, how well information meets their needs, and why people adopt certain behaviours.

Individuals may engage in a wide range of information behaviour other than information seeking, depending on the nature of the illness, the nature of the information and the context within which they access and use information. However, previous research depicts information seeking and, to a limited extent, information avoidance, as the only forms of health information behaviour. The current study seeks to close this gap by exploring whether individuals faced with a life-threatening and stigmatising health condition such as HIV/AIDS, could exhibit other patterns of health information behaviour that have not been identified in previous HIB research. This knowledge could help in developing a rich, detailed, and nuanced model that suggests ways in which information behaviour might be manifested in life-threatening, challenging and stigmatising contexts. It is the view of this researcher that Information Behaviour (IB) research focusing on people experiencing life-threatening and stigmatising health conditions, in this case HIV/AIDS, is likely to generate insights into how to better design and implement information products and services that are sensitive, responsive and address the needs of people in these circumstances.

Studies in relation to HIV/AIDS-related information in the UK, have mainly focused on sources of HIV/AIDS information and levels of HIV/AIDS awareness and knowledge, with the exception of Minion's (2010) study, which aimed at generating understanding about ways the social context of being positive and gay influences information practices among gay men. Thus there is inadequate knowledge about the information experiences of PI/A HIV/AIDS, including the patterns of their information behaviour and the factors that shape it. This study sets out to address this gap, and suggests that understanding the IB of this group of information users may help the people involved, including health-care providers, information professionals and system developers, to develop optimal information products, interventions and services, geared towards the prevention and management of HIV/AIDS.

CHAPTER 3-METHODOLOGY

3.1. Introduction

Chapter two reviewed existing research and revealed that we do not yet have models of information behaviour incorporating the lived information experiences of persons infected with, or affected by, HIV/AIDS (PI/A HIV/AIDS).

This chapter consists of a general overview of the theoretical exposition of philosophy and methodology, including the research paradigms and research designs that were available to the researcher. It includes a review of research paradigms and identifies the conditions in which each can be applied in research with a view to positioning the current study in the general research framework.

This chapter also provides an overview of qualitative and quantitative research designs and a description of the conditions under which they can be adopted.

3.2. Research paradigms

This section provides an overview of the common paradigms in social science research in order to establish the most suitable research paradigm for the current study. The motivation for conducting a review of existing paradigms stems from scholars such as Guba and Lincoln, who underscored the importance of paradigm issues by suggesting that no inquirer should go about an inquiry without being clear about what paradigm informs the inquiry (Guba and Lincoln, 1998).

In the context of this study, a paradigm is construed as encompassing elements of ontology, epistemology, as well as methodology (Lincoln, 1985; Bryman, 1988; LeCompte and Schensul, 1999b; Punch, 2005; Pickard, 2007), or as an entire constellation of beliefs, values and techniques, shared by members of a given scientific community (Kuhn, 1970).

Thus, paradigm issues are crucial as they inform and guide the research approach, including what should be studied, how research should be conducted and how results should be interpreted.

The major questions that help to define a research paradigm include the ontological question (what is the nature of the phenomena or entities, or social reality that I wish to investigate?); the epistemological question (what is the nature of the relationship between the knower and the known?); and the methodological question (how can we come to know it?) (Lincoln, 1985).

Sections 3.2.1-3.2.5 examine the positivist, critical, ecological, social network and interpretivist paradigms in the light of the ontology, epistemology and methodology of each.

3.2.1 The positivist paradigm

The positivistic research paradigm is rooted in positivism which assumes the existence of objective, independent and stable reality, available for discovery and analysis. Hence positivism entails applying the rules and assumptions of the biological sciences in social sciences research (LeCompte and Schensul, 1999b; Pickard, 2007). Positivists argue that reality is observable and understandable and if research is conducted with a properly representative sample of participants, the findings that a researcher obtains are true and can be generalised to the study population as a whole. Positivists consider that, as in the field of science, knowledge can only be based on what can be observed and experimented on (LeCompte and Schensul, 1999b; Bryman, 2004; Pickard, 2007).

Positivists also assume a distinct conceptual and social separation between the researcher's influence and the object or event being studied. Hence, positivists emphasise objectivity and demand that the researchers withhold their biases and prejudices about the research and people involved in it by controlling any outside influences on the research results. Positivists view the researcher as an objective observer who can stand apart from that which is being observed, and report on the reality which is discovered through this observation (LeCompte and Schensul, 1999b; Bryman, 2004; Pickard, 2007).

The key tenets of positivism are measurement and objectivity, resulting in a focus on quantitative data. The associated style of reasoning is deductive, where research begins with theories or models, variables are defined for study, and their relationships are predicted through framing hypotheses that are then tested. Consequently positivist approaches focus on prediction, control, explanation and verification. The ultimate

purpose of positivist approaches is providing explanation leading to prediction of causal relationships.

The current study could not be conducted from a positivist view because there was no existing theory which could be used to develop and test hypotheses on HIV/AIDS-related information behaviour which provided a sufficiently detailed and nuanced focus.

Secondly, human behaviour cannot be predicted using standard measurement.

Furthermore, the current study focused on a complex and hard to reach population of PI/A HIV/AIDS which could not be objectively studied in an experimental setting. Given the nature of the population and the aim of the current study, positivist approaches were not feasible.

3.2.2 The critical paradigm

Critical theorists are guided by concepts of class, power and equity. They investigate ways in which the history and political economy of a nation, state, or other systems exert direct or indirect domination over the political, economic, social, and cultural expressions of citizens or residents (LeCompte and Schensul, 1999b). Critical theory guides investigation into the sources and dimensions of inequality within such systems. Theorists focus on ways in which gender, class, culture, race, ethnicity, and power intersect to shape inequality. In this paradigm, researchers are expected to function as intellectual advocates and activists. Researchers are also expected to use tools of research to discover inequalities and to find ways – whether through research, dialogue, intervention, political action, or policy change – to bring about change in inequitable distributions of power, cultural assets or other resources (LeCompte and Schensul, 1999b).

Critical theorists, like positivists, believe that researchers can capture accurately the specific historic and geographical phenomena they study. However, they also assume that the interpretation of cultural products they examine is influenced by the context in which they are produced and reproduced.

Critical research is expected to demonstrate how, and in what ways, participants are in positions of domination or subordination and how they can act to change both their own situation and that of others. Critical research is intended to be empowering. Thus researchers are also expected to enhance participants' individual and group potential for

accessing important social and economic resources, for entering the political arena, for engaging in self – expression and for becoming active in shaping their own future.

Since the final aim of critical research is to call attention to inequitable actions and policies of the dominant social institutions and to engage in activities guided by research findings to bring about change, conducting critical research requires congruence among the aims, objectives and values of the researcher and those of the group involved in the study (LeCompte and Schensul, 1999b).

The critical paradigm could not be adopted for the current study because it neither set out to call attention to inequitable actions and policies of the dominant social institutions, nor identify flaws in structures in order to advocate transformation. The current study sought to generate insights into the complex and delicate HIV/AIDS lived information experiences of PI/A HIV/AIDS. It required a research paradigm which affords the researcher ways of attaining an intimate appreciation of the dilemmas, frustrations and challenges associated with accessing information from the respondents' point of view.

3.2.3 The ecological Paradigm

The key tenets of the ecological paradigm include viewing individuals as functioning in a social context that influences their behaviours. The context consists of the human and physical environment in which events take place. It includes social levels such as family groups, peer networks, school or work settings, community and the wider society, and sectors such as social, technical and environmental (LeCompte and Schensul, 1999b).

Ecologically-oriented research also views institutions or sectors in the community as systematically related to, and affecting, one another. They believe that change should be introduced in all levels of sectors simultaneously and argue that research should identify those contextual elements with the greatest influence on individual or institutional behaviour (LeCompte, 1999).

Ecologists emphasise adaptation rather than conflict. Hence, they look for continuous accommodation among individuals and institutions, and seek to understand how social systems persist and adapt to conflict, as well as how they change.

Although HIV/AIDS lived information experiences can only be understood in the context in which the illness takes place, this study did not focus on adaptations and conflicts within institutions that deal with HIV/AIDS. Rather, it sought to study and understand human information behaviour at an individual level within the context of being infected with, or affected by, HIV/AIDS. Hence a paradigm that has finding ways in which social systems persist and adapt to conflict, and how they change as its core values, was not appropriate for the current study.

3.2.4 The social network paradigm

The social network paradigm that has evolved over the past 40 years, has been used in studies of family systems and adaptation, and in diffusion studies concerned with the flow of innovation, information, or infection in populations (LeCompte and Schensul, 1999b).

Investigating social networks provides researchers with the opportunity to observe and document important exchanges between and among individuals, to explore where these exchanges happen, and to determine what factors might influence them. Thus it allows the researcher to situate individuals within their families, among their peers, and in relation to representatives of other social or cultural institutions.

Although understanding the social networks of PI/A HIV/AIDS could, to a certain extent, throw some light on HIV/AIDS-related information experiences, the social network paradigm could not be employed to unearth complex HIV/AIDS-related individual information experiences including dilemmas, frustrations, challenges, connects and disconnects that people experience. Thus focusing on social networks would not generate rich insights into HIV/AIDS-related information behaviour. Consequently, the social network paradigm was not deemed suitable to be adopted for the current study.

3.2.5 Interpretivism

Bryman (2008) defines interpretivism as a term given to a contrasting epistemology to positivism. It is based on the view of writers who are critical of the application of the scientific model to the study of the social world. They postulate that the subject matter of the social sciences – people and their institutions – is different from that of the natural sciences and suggest a different logic for research procedures, emphasising the subjective meanings of social actions.

Crucial to interpretivist researchers is the ‘social construction of reality’ (LeCompte and Schensul, 1999b; Bryman, 2004; Pickard, 2007). Interpretivism is a broad term that encompasses a number of different paradigms all concerned with the meanings and experiences of human beings. Hence the interpretivist philosophy, where the constructivist paradigm fits, takes a different view of reality from positivists. Unlike positivists, who assume that reality has some tangible referent and agreement can be achieved on its nature, given time and careful research, interpretivists believe that what people know and believe to be true about the world is constructed as people interact with one another over time in a social setting. Unlike positivists, for whom research results are true, at least in a probabilistic sense, and are empirically verifiable, interpretivists argue that the social constructions of individuals and groups are not more or less true in an absolute sense, but simply more or less informed and /or sophisticated (Lincoln, 1985). For an interpretivist, the constructs are not fixed or immutable; they can be altered through dialogue and alterations can lead to new constructions or views of reality and new ways of acting.

Another key component of the interpretive paradigm is that it always defines shared constructs and meanings as situated, implying that they are located in, or affected by, the social, political, cultural, economic, ethnic, age, gender, and other contextual characteristics (LeCompte and Schensul, 1999b; Flick, 2002; Pickard, 2007). These characteristics influence how individuals think, behave and present themselves. Hence, interpretivists view participants’ behaviour in conjunction with the social and political status of each participant.

Unlike positivists or critical theorists, interpretivists stick to local meanings and find it difficult to tell only one story. They instead present complex accounts as poly-vocal texts or stories told in the voices of many different people (LeCompte and Schensul, 1999b).

Furthermore, interpretivist approaches are inherently participatory, because meaning can be created only through interaction. Hence, interpretivists participate in the lives of the research participants in order to observe the process of creating constructs, ideas, and meanings as they occur. Similarly, authentic or valid constructs or ideas can be elicited and refined only through interaction between the researchers and participants. Therefore, the findings of interpretivists are created and recreated as the research proceeds.

Interpretive approaches are not activist-oriented. Thus interpretivists are not necessarily expected to produce results that commit to action. That notwithstanding, results from interactions in the research site can produce a deep sense of understanding of a particular social problem which may lead to specific directions of action.

Interpretivists emphasise the generation of shared meanings and the recognition of the importance of local contexts and cultures in understanding human behaviour and beliefs. Interpretivists favour naturalistic enquiry, embrace an inductive style of reasoning and emphasise qualitative data. They emphasise that meanings are socially constructed, situated and therefore relative to a specific context. They are not fixed, but are negotiated, multiply-voiced and participatory. The interpretivist tradition is concerned with individual contexts and therefore research can only be particularised, and generalisation in the traditional scientific sense is not possible. The findings are only transferable based on contextual applicability.

Interpretivism is a philosophy which is concerned with meaning and experience of human beings, particularly where human beings are constantly involved in interpreting their changing world, which adopts inductive approaches to research in a natural setting. Thus interpretivism provided the ontological, epistemological and methodological framework for the current study, which sets out to explore the 'lived HIV/AIDS information experiences' including HIV/AIDS related information behaviour and factors that shape it.

3.2.6 Summary

The review of research paradigms above provided the frame of reference including the concerns, focus, procedures, and processes underpinning the choice of a paradigm for any piece of research. The review of the research paradigms available to this researcher revealed that positivists consider that, as in the field of science, knowledge can only be based on what is observed and experienced. Hence the key positivist precepts are measurement and objectivity resulting from a focus on quantitative data. The associated style of reasoning is deductive where the argument moves from general principles to particular instances. Hence positivist research entails beginning with theories and models, defining variables for study and predicting their relationship through framing hypothesis that are then tested for purposes of making generalisations based on findings. The review also revealed that positivists adopt experimental design and emphasize cause and effect.

Validity and reliability are key constructs of positivist research paradigms. On the other hand the interpretivist philosophy is concerned with meaning and experience of human beings. The ideology of interpretivist is that human beings are constantly involved in interpreting their changing world. Hence intrerpretivists believe that the social world is constructed by people and is therefore different from the world of nature. They conduct research in natural settings, adopt inductive approaches to research and theory and stress the use of qualitative data.

In view of the ontological, epistemological and methodological viewpoints of positivist and interpretivist paradigms, the current study which seeks to explore the lived HIV/AIDS information experiences including HIV/AIDS related information behaviour and factors that shape it could best be carried out from an interpretive view point.

3.3. Research designs

Section 3.2 reviewed the research paradigms. The aim in so doing was to identify a philosophical frame for conducting the current study. Sections 3.3 consist of a review of research designs available to this researcher with a view to identifying the most suitable framework for generation and analysis of data for the current study.

A research design describes a set of guidelines that connect theoretical paradigms to strategies of enquiry and methods for collecting empirical material (Denzin, 2000). Thus a research design situates the researchers in the empirical world of experience and connects him/her to specific sites, persons, groups and institutions. LeCompte and Schensul (1999b) observed that research designs are to researchers as roadmaps and vacation plans are to vacationers. Like a good vacation plan, a good research design saves time, money, headaches, and unpleasant surprises and permits the anticipated aim of the research to be achieved.

In this discussion, the two most common research designs in social science research – qualitative and quantitative designs – are examined (Creswell, 1994; LeCompte and Schensul, 1999b; Mason, 2002; Bryman, 2004; Pickard, 2007).

3.3.1 Quantitative research designs

Quantitative research begins with a theoretical framework established from a literature review, from which one or more hypotheses emerge and the variables within the hypotheses are identified. Quantitative research design demands a detailed plan before research begins and follows a distinctive research strategy which entails the collection of numerical data, exhibiting a view of the relationship between theory and research as deductive and having an objectivist conception of social reality (Bryman, 2004; Pickard, 2007).

Quantitative research designs are therefore construed as ones that emphasise quantification in the collection and analysis of data, and adopt a deductive approach to the relationship between theory and research, in which emphasis is placed on testing of theories.

Hence qualitative research designs incorporate the practices and norms of the natural scientific model of positivism, and represent a view of social reality as an external objective reality that can be measured or experimented upon (Mason, 2002; Bryman, 2004; Pickard, 2007).

3.3.2 Quantitative design types

The most common quantitative designs used in social sciences include experimental, quasi-experimental, population and survey designs (LeCompte and Schensul, 1999b). A brief description of each design is given below.

Population and sample survey study designs

Population and sample survey designs are employed in quantitative research when the problem and context are clearly known; when a target population's characteristics have been identified, particularly where members can be listed by name or discretely identified (LeCompte and Schensul, 1999b).

Sample surveys are used to elicit a limited amount of information from a large population whose characteristics, including the language they use, their age, their location and other demographic factors, as well as their accessibility and willingness to answer questions, are already reasonably well known (LeCompte and Schensul, 1999b).

On the other hand, population surveys involve asking questions to an entire group of people. However, where populations are very big and resources prohibit surveying every one, sample surveys are used instead. Data generated from the smaller group are assumed to characterise what would have been collected from the larger group.

Survey research designs are conducted following certain principles of probability sampling, instrumentation, data analysis and presentation. Hence surveys are meticulously conducted to ensure that the results of the survey can be generalised to the entire population (LeCompte and Schensul, 1999b). If the purpose of the research is to determine how a representative sample of people from a particular community feels about a problem or issue, survey research design is the most appropriate choice.

Experimental and quasi-experimental designs

Experimental designs are employed in quantitative studies when there is hypothesis or prediction about the expected results; when it is possible to create a comparison group through random assignment of units; and when rigorous control over conditions of treatment or implementation is attainable (LeCompte and Schensul, 1999b). Experimental and quasi-experimental designs are mainly used by natural scientists, medical personnel, psychologists, educational researchers, evaluators and funding agencies (LeCompte and Schensul, 1999b). Experimental designs are used when research questions focus on determining whether an intervention or a treatment has an effect by taking measurements before and after and comparing the results to a comparison or control group that did not get the intervention.

Summary

An overview of the quantitative designs, such as survey and experimental designs has revealed that the current study, which sought to generate knowledge about sensitive and personal information experiences, could not be conducted using quantitative designs because it neither set out to prove a hypothesis nor establish an ultimate truth. Thus objective tests, self-reported questionnaires, and rating scales of the quantitative approach could not be applied to the current study because they could not unearth everyday nuanced challenges, dilemmas and frustrations, of human information behaviour, including

accessing and using HIV/AIDS-related information. Furthermore, lack of control and inability to manipulate field settings rendered experimental designs inappropriate.

3.3.3 Qualitative research designs

The emergent nature of qualitative research does not allow for a detailed research design before the research begins – it must unfold, cascade, roll out, or emerge (Lincoln, 1985). Consequently, qualitative research designs are characteristically exploratory, fluid / flexible, data-driven and context-sensitive. The designs are not etched in stone at the beginning of the study but they cascade, roll out, or emerge and are recursive. Therefore decisions about design are on-going and grounded in the research practice, process and context of research itself (Mason, 2002; Gorman and Clayton, 2005; Pickard, 2007). An emergent design is an integral part of qualitative research. It is based on the premise that the researcher ‘does not know what she does not know’ at the beginning of the study (Lincoln, 1985). It is not easy to establish the means by which the unknown could manifest itself to the researcher during the course of the study. Thus an iterative model that allows the design to emerge as the study progresses is most suitable when conducting qualitative research. Within the emergent design, data collection is based on analysis of preceding data and identification of concepts and ideas that require further and deeper investigation.

Gorman and Clayton (2005) also advised that although the qualitative research approach is recursive: moving forward and backward throughout the life of the project. It must also be moving toward a finite end, building steps towards a conclusion at each stage of the research pyramid (Gorman, 2005). Consistent with Gorman and Clayton’s advice, the current researcher worked up the pyramid from generalities at the base, starting with a broad general field of interest, and progressively narrowing down until a tightly focused study was reached at the pinnacle.

Researchers such as Pickard (2007) and Maykut and Morehouse (1994) observed that human lives and their interpersonal relationships create complexities that cannot be understood by one-dimensional and reductionist approaches. In the light of the above observation, it was felt that the current study, which sought to explore the nuanced lived information experiences of PI/A HIV/AIDS, could best be conducted using qualitative designs because they provide a framework for studying complex human experiences. The

design was appropriate for the current study because it allowed the researcher to be involved with participants so that she was able to have a deeper understanding of HIV/AIDS-related information experiences from the perspectives of the participants. An emergent design also allowed the researcher to discover interesting and salient issues that she could not anticipate.

3.3.4 Qualitative design types

This section consists of a brief overview of the most frequently used qualitative research designs. The aim in so doing was to identify the most appropriate design for the current study. An overview of case study, action research and ethnographic designs is given below.

Case study designs

Case study designs are employed to study a functioning specific, that is to say, a system that operates within well-defined boundaries (Pickard, 2007). The main difference between case study research and ethnographic research is the extent to which the researcher immerses himself or herself in the life of the social group under study (Myers, 1999). In case study research, the primary source of data is interviews supplemented by documentary evidence such as annual reports, minutes of meetings and so forth; whereas in ethnography, the main data generation technique is participant observation, although other methods of collecting information concerning the context are often used (Pickard, 2007). Creswell (1998) argued that, although conducting an ethnographic study may on the surface appear to be very similar to case study research, it is the extent to which the researcher is immersed in the context that is the real and most obvious difference. He further pointed out that while the focus of ethnography is to describe and interpret a cultural and social group, the focus of case study research is to develop in-depth analysis of a single case. Whereas a case study site is often visited at regular intervals to engage in data collection which can be largely predefined, ethnography demands prolonged engagement within the context.

The above discussion suggests that although PI/A HIV/AIDS may be a case, PI/A HIV/AIDS's information behaviour could not be a case because it does not provide sufficient boundaries. Consequently, the case study design is not appropriate for the

current study. Secondly, case study designs do not provide prolonged engagement in the research setting as the case study site is visited at regular intervals to engage in data collection.

Action research designs

LeCompte and Schensul (1999b) observed that action research designs are employed in qualitative studies that are conducted in partnership with members of the community studied with the purpose of bringing about structural or cultural change. They argued that action research is conducted with clear community or institutional change in mind. Thus action research could be conducted to address structural inequalities such as limited or poor quality mental health services for poor rural residents, gaps in computer and library resources in urban schools, or preferential hiring in government organisations. Although the aim of the current study is to generate insights that could be used to improve HIV/AIDS-related information service provision, action research was not adopted because the study was not concerned with structural or cultural changes, but rather on understanding the information behaviour itself.

Ethnographic designs

LeCompte and Schensul (1999b) argued that ethnographic designs are employed when parameters and outcomes of a population, process, problem, context or phenomenon are unclear, unknown or unexplored. Ethnographies employ open-ended interviews and participant observation for data generation, work with a defined group, and use cultural concepts to guide research and to explain or interpret data. Hence ethnographies are ideal for answering the question about what is happening in a programme or with individuals (LeCompte and Schensul, 1999b). The choice of an ethnographic design for the current study was consistent with LeCompte and Schensul (1999b) who observed that ethnographies ought to focus on what makes people in the study tick, including how they behave, how they define their world, what is important to them, why they say and do what they do, and what structural or contextual features influence their thoughts, behaviour, and relationships. The reasons for the choice of ethnography for the current study are discussed in detail in section 4.2, whilst section 3.4 below provides a brief overview of ethnographic approaches.

3.4. Ethnography

Ethnography is a qualitative research approach rooted in anthropology that attempts to describe people's perceptions of meaning and events within the context they take place (Spradley, 1979; Agar, 1986; Hammersley and Atkinson, 1995; Hammersley and Atkinson, 2007). It is a scientific approach to discovering and investigating social and cultural patterns and meanings in communities, institutions and other social settings. Conducting an ethnographic study requires that researchers learn from people as informants rather than regard them as subjects (Spradley, 1979). Informants become teachers for ethnographers who attempt to understand the informants' meaning of the world from their point of view and present it to the professional audience. Schensul et al. (1999) described the ethnographer's focus on discovering what people do and why they do it, before assigning meanings to behaviours and beliefs, as a primary difference between ethnography as a science and other social and behavioural science methods of investigation. The characteristics of ethnographic approaches, including conducting research in a natural setting, intimate face-to-face interaction with participants, accurate representation of participants' perspectives and behaviours, use of inductive, interactive and recursive data collection, using multiple data sources, framing all human behaviour within a social-political and historical context, and using culture as a lens through which to interpret results, make ethnography's potential contribution to research profound. However, as Herbert (2000) observed that ethnography is an underused methodology in geography, the same could be said about Library Information Science research. The neglect is injurious because it may result in research findings that are impoverished, and lack the rich thick descriptions and insights into processes and meanings that sustain and motivate social groups and human interactions and actions.

3.4.1 Definition of ethnography

There is not one single standard definition for ethnography because ethnography is linked to a complex history. Its origins can be traced in the work of nineteenth century anthropologists who travelled to observe pre-industrial cultures (Silverman, 2006).

Researchers in the field of social and cultural anthropology, such as Evans-Pritchard (1937), Malinowski (1929), and Marcus and Clifford (1986), who were concerned with the difficulties of cross-cultural understanding, developed the notion of participant observation in long term field-work. They carried out ethnographic research with different human groups as a means of documenting the beliefs and practices of other cultures in order to be able to see the world from an indigenous point of view (Malinowski, 1922; Geertz, 1973).

Ethnography was then contrasted with, and was usually seen as complementary to, ethnology which referred to the historical and comparative analysis of non-western societies and cultures (Hammersley and Atkinson, 2007). Over time, ethnology fell out of favour because anthropologists began to do their own field-work, with ethnography coming to refer to an integration of both first hand empirical investigation and comparative interpretation of social organisation and culture (Parker and Ehrhardt, 2001b).

Present day practitioners conduct ethnographies in organisations and communities of all kinds. For instance, ethnography is employed by sociologists, psychologists, educators, quality control researchers, market researchers, and others to study phenomena such as schooling, public health, rural and urban development, consumers and consumer goods. Contemporary ethnographers go beyond reporting details of events and details of experiences and attempt to explain how the events and experiences represent 'webs of meaning' and cultural constructions in which people live (LeCompte and Schensul, 1999b; Myers, 1999).

Ethnography's complex history explains its lack of a clear standard definition. However, lacking a single standard meaning does not undermine the value of ethnography as a label. In view of this complex history, a single definition of ethnography cannot capture all of its meaning in all contexts. This explains why authors such as LeCompte and Schensul (1999b), Hammersley and Atkinson (1995), Hammersley and Atkinson (2007), Myers, (1999) and Silverman(2006) focused the definition of ethnography at a practical level, including what ethnographers do, the sorts of data they usually collect, and the kind of analysis they deploy to handle the data.

Ethnography is described as a field-work approach where ethnographers seek to place phenomena studied in their social and cultural context by immersing themselves in the life of the people they study. Conducting an ethnography involves an ethnographer

participating, overtly or covertly in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact collecting whatever data are available to throw light on issues that are the focus of the research (Lewis, 1985; Hammersley and Atkinson, 1995; Van Maanen, 1996; LeCompte and Schensul, 1999b; Myers, 1999; Brewer, 2000; Delamont, 2004; Goodley, 2004; Hammersley and Atkinson, 2007; Pickard, 2007). Spending a significant amount of time in the field was reported to be helpful to ethnographers as far as helping them to develop an intimate familiarity with the dilemmas, frustrations, routines, relationships and risks that are part of everyday life.

In addition to immersion and spending long periods in the field, ethnography facilitates studying people in naturally occurring circumstances and affords researchers an opportunity to collect data which captures the social meanings and ordinary activities directly in the settings where they take place. This implies that peoples' actions and accounts are studied in everyday contexts rather than under conditions created by the researcher, such as an experimental set-up or highly structured interview situations (LeCompte and Schensul, 1999b; Brewer, 2000; Hammersley and Atkinson, 2007; Pickard, 2007). Ethnography's emphasis on studying the social world in its natural state undisturbed by the researcher stands out as a major distinguishing feature of this approach.

Bow (2002a) added another dimension to the definition of ethnography when he pointed out that although it is one of the most flexible techniques for doing research, there is no single way of undertaking an ethnography. Hence ethnography not only potentially combines a number of techniques including interviewing, focus groups, observation and questionnaires, but also provides the flexibility to emphasise some techniques over others, and to leave some techniques altogether, depending on the requirements and constraints of the research itself, such as time, money and resources. This definition informed the current study in which the researcher emphasised open-ended interviews and participant observation rather than surveys.

In addition to combining many techniques, ethnography adopts a flexible and reflexive research design with the researcher seeking to be totally open to the research setting (Hammersley and Atkinson, 1995; LeCompte and Schensul, 1999b; Brewer, 2000; Gorman and Clayton, 2005; Williamson, 2006). Thus the research design of the current study was non-linear and iterative. Although there was planning, including conducting a

literature search and review, designing tentative research questions and developing a data collection plan, various elements were interwoven, with the development of one influencing decisions about others.

However, in the context of three-year PhD project, the researcher could not conduct the ethnographic study in a traditional sense, hence; a compressed ethnographic design was adopted.

3.4.2 Compressed ethnographic designs

Given the requirement by traditional ethnography for researchers to spend years in the field, this study adopted a compressed ethnographic research design with similar elements and techniques to traditional ethnographic methods apart from the duration of the study (LeCompte and Schensul, 1999b; Roslina, 2004). Compressed ethnographic research designs were developed for occasions when resources of time and money do not permit a fully-fledged ethnography (LeCompte and Schensul, 1999b). Hence compressed ethnographies entail modifications of traditional ethnography that accommodate shortened timelines.

Similar approaches have been applied in the context of information systems in organisations. For example, Roslina (2004) conducted an ethnographic study to evaluate retrieval features in a much shorter period because the context of an information system in an organisation could not permit the researcher to conduct ethnography in its traditional sense.

It was possible for the current study to employ compressed ethnographic methods because it met the conditions for conducting compressed ethnographic study as suggested by LeCompte and Schensul (1999b). First, the researcher was familiar with the field setting (i.e., persons infected with, or affected by HIV) because of her background as a Ugandan who had experienced the effects of HIV/AIDS on her country, community and family. Secondly, the researcher speaks English fluently so she had no requirement for extra time to learn the language. Furthermore, the study focused on one aspect of the culture, i.e., HIV/AIDS-related information behaviour. In addition the researcher was able to work with cultural experts (people who lived with HIV for a long time as well as HIV support workers) from the setting. This helped to establish the context for data collection and

avoid mistakes resulting from the researcher's lack of familiarity with the setting, speed up the work and ensure validity. Finally, the researcher employed data collection techniques, namely participant observation and individual in-depth interviews, which were suitable to use in a brief period of time.

3.5. Convergence of qualitative and quantitative research designs

Although the discussion has been about the differences between qualitative and quantitative strategies, the distinction is not a hard-and-fast one (Mason, 2002; Bryman, 2004; Ritchie and Spencer, 2004). Therefore there can be value in combining qualitative and quantitative data in a single study. Consequently, studies that have the characteristics of one research strategy may also have characteristics of another. Flick (2002) also argued that the combination of multiple methodological practices, empirical materials and perspectives in a single study adds rigour, breadth, complexity, richness and depth to any inquiry in qualitative research.

In light of the above, researchers can adopt multi-method approaches involving the use of a wide range of interconnected interpretive practices and collection of a variety of empirical materials that describe routine and problematic moments and meanings in individual's lives in order to provide a better understanding of the subject at hand.

3.6. Conclusion

Chapter three has provided a general theoretical overview of the philosophy and methodology, including the research paradigms and research designs that were available to this researcher for the current study.

The review revealed that the current study, which sought to explore the "lived information experiences" of PI/A HIV/AIDS, could best be conducted using interpretive paradigm, incorporating an ethnographic design. An interpretive paradigm is appropriate for the current study because its ideology, that human beings are constantly involved in interpreting their changing world and that the social world is constructed by people could best support the researcher's need to generate rich insights in HIV/AIDS information behaviour from the point of view of PI/A HIV/AIDS. Ethnography offers a suitable research design because it provides a framework that can enable people to freely talk about

sensitive and personal feelings, thoughts and experiences related to access and use of HIV/AIDS-related information.

CHAPTER 4-RESEARCH APPROACH

4.1. Introduction

Chapter three provided a general exposition of research philosophy and methodology, including the research paradigms and research designs that were available to the researcher. The aim in doing so was to position the current study in a more general research framework. Chapter four describes the research approach adopted for the current study. It details what the researcher actually did, and explains how and why she did it. Chapter four provides a justification of the choice of the research approach, and describes the data generation process, including sampling methods, the study sample, ethics, and analytical methods. Chapter four sets the background for Chapters five, six and seven where first level data analysis and is presented, and chapter eight, which presents the interpretation of the results.

4.2. Justification for the choice of an interpretivist research paradigm

The review of the five paradigms presented in Chapter three led to the decision to employ an interpretive approach for the current study, which sought to generate in-depth understanding of the information behaviour of PI/A HIV/AIDS.

Interpretivist approaches were appropriate because they potentially provide a framework for studying the experiences and social action of human beings from their point of view.

The interpretivists' emphasis on studying phenomena in its natural setting was favourable for the current study because it sought to go beyond physical observable behaviour in order to understand and appreciate HIV/AIDS-related information experiences as understood by PI/A HIV/AIDS in England.

An interpretivist approach is valid for this exploratory study because it seeks to gain an appreciation of the daily information experiences as understood by PI/A HIV/AIDS.

The interpretive approach could generate shared meaning about HIV/AIDS-related information behaviour because, as Williamson (2006) observed, when people share the experience of a certain disease such as HIV within a particular society, it is likely that some shared meanings will emerge.

An interpretive approach, when applied to the current study, could generate rich insights into HIV/AIDS-related information behaviour. It is hoped that such insights could possibly inform future HIV/AIDS-related information management practice, policy, and strategy, lead to improved HIV/AIDS information service provision, and ultimately contribute to the fight against HIV/AIDS.

In view of the arguments for the choice of interpretivist approaches, the current study was guided by an interpretivist model, particularly the social constructivist framework which is premised on social construction of meanings in order to discover the shared meanings and experiences of persons infected with, or affected by, HIV in relation to HIV/AIDS-related information. Research was conducted in a natural setting at the HIV/AIDS support group premises, inductive approaches were embraced and qualitative data were generated.

4.3. Justification for choice of an ethnographic approach in the study

According to LeCompte and Schensul (1999b), the decision to use an ethnographic design is strongly influenced by the characteristics of the population, conditions of the research setting and what the researcher wants to know. Given the characteristics and conditions of the population, as well as the need to generate an understanding of HIV/AIDS-related information behaviour from the point of view of people affected by the disease, the current study adopted an ethnographic approach. The main reasons for choice of ethnography for the current study are discussed under the following headings, which are based on features offered by this approach:

- immersion and participant observation;
- in-depth understanding of the study phenomena;
- use of ethnography in HIV/AIDS-research;
- use of ethnography in Library and Information Science research;

- potential to study hard to reach populations;
- ability to employ many research techniques;
- flexible research design.

These reasons are expanded on below.

4.3.1 Immersion and participant observation

This study sought to gain an in-depth understanding of lived HIV/AIDS-related information experiences and information behaviour. This could most effectively be achieved through immersion in the research site for an extended period of time. Thus the researcher immersed herself in the research site for an extended period of time, from March 2010 to May 2011, in order to gain an intimate appreciation of what people say and think about, as well do with, HIV/AIDS-related information. Consistent with this reasoning is Myers' (1999) observation that the profound strength of ethnographic research is that it is the most 'in-depth' or intensive research method possible because immersion in the research site leads to an intimate appreciation and familiarity with dilemmas, frustrations, routines, relationships, and risks that are part of the everyday life of the participants. Ethnographic techniques such as immersion and participant observation were particularly relevant to this study because they enabled the researcher to gain access to private and personal information experiences of PI/A HIV/AIDS. This facilitated insightful examination of HIV/AIDS-related information behaviour, as well as identification of factors that enhance or impede this behaviour.

The value of immersion was further elaborated by authors such as Hammersley and Atkinson (1995), Hammersley and Atkinson (2007), Myers (1999), and Pickard (2007), who observed that, when ethnographers typically live with participants, they become acquainted with them, understand the dynamics of their interactions, understand how they relate to their physical and material environment, and how they elicit the meanings, goals and objectives that are important to the study.

By immersing herself in a community of PI/A HIV/AIDS and participating in their lives, the researcher was accorded the opportunity to gain rich insights into the nuanced ways in which people experience access to, and use of, HIV/ AIDS-related information in their daily lives. Immersion and participant observation enabled the researcher to share as

intimately as possible in the lives and activities of people affected by HIV/AIDS. The researcher's involvement with participants not only unearthed 'lived HIV/AIDS-related information experiences', but provided insights into what needs to be done to address contextual factors especially relating to HIV/AIDS-related information that hindered access to, and use of, HIV/AIDS-related information. This was consistent with Lofland (1995) who observed that ethnographers' insights emerge from their progressive socialisation into the lives of the study group. Ethnographic approaches offered deep and rich insights into complex HIV/AIDS-related information behaviour which might otherwise have remained hidden.

4.3.2 Use of ethnography in HIV/AIDS research

Ethnographic approaches were also selected for the current study because successful research on HIV/AIDS had already been conducted using them. Indeed, Parker and Ehrhardt (2001b) reported that the growing importance of ethnographic approaches in social and health-related research was particularly realised when the HIV/AIDS epidemic became truly global and was spreading rapidly around the world, in some cases devastating whole societies.

The urgency of establishing effective prevention programmes had become obvious – yet it was evident that such efforts would be doomed to fail if they were not embedded in a deep understanding of the cultural and social context of relevant behaviour patterns. Thus ethnographic studies of injecting drug users, and men who have sex with men, provided an understanding of the HIV/AIDS epidemic which was vital for the development of prevention, treatment and other related interventions (Parker and Ehrhardt, 2001b). For example, McCoy et al.(1996) employed ethnography to study the relationship between sex, drugs and the spread of HIV; Parker (2001b) and Maher (2002) studied drug users in relation to AIDS; Minion (2010) used ethnographic approaches to study the information world of gay men living with HIV/AIDS.

Ethnographic approaches have thus proved to be an important alternative to other methods of studying behaviour, because they help to highlight social phenomena that might otherwise be taken for granted, as they are made visibly problematic by participants themselves. The importance and usefulness of ethnographic research in HIV/AIDS dates back to the 1980s, when early responses to communities in countries such as the United

States, Australia, Canada, and many European countries were based on insider knowledge that provided descriptive or observation databases for the design of culturally appropriate prevention programmes and intervention strategies (Parker and Ehrhardt, 2001b).

For instance, in the 1980s, one of the important contributions of ethnographic approaches to HIV/AIDS research was to problematise the very categories that had been used in many of the epidemiological studies of the epidemic, calling attention to the fact that many of the classifications used to describe population groups thought to be at increased risk of infection, might in many contexts have little or no meaning from an indigenous social or cultural perspective (Parker and Ehrhardt, 2001b). Likewise, ethnographic studies of cultural meanings carried out by anthropologists were crucial in deconstructing categories such as homosexuality and gay identity and drawing attention to a broader population of men who have sex with men but who may not share any notion of sexual identity or consider themselves to be members of a distinct sexual community (Parker and Ehrhardt, 2001b). Similarly, detailed ethnographic studies were equally important in calling into question preconceived notions concerning prostitution and prostitutes. Consequently, ethnographic approaches paved the way for a growing reflexivity concerning practices seeking to address the epidemic by revealing HIV/AIDS as a complex social phenomenon that includes not only patients and target populations, but also researchers, programme officers, activists, policy makers, information designers and managers and other social actors as part of a multidimensional, on-going form of social interaction, production and reproduction that must ultimately be understood in order to address the epidemic and the challenges it poses.

Such studies support the view that an ethnographic approach is suitable for the current study, which seeks to understand the lived information experiences of person infected with, or affected by a debilitating illness such as HIV/AIDS.

4.3.3 Use of ethnography in Library and Information Science research

Another justification for choice of ethnographic approaches for the current study lies in the fact that Library and Information Science research and information service design and provision have over the years benefitted from rich insights provided by ethnographic studies. Ethnographic user studies in Library and Information Science research include those of Shapiro (1989a), who studied general practitioners' information needs:

Williamson (2002), who studied information seeking for online investors as well as information seeking of women with breast cancer; Cunningham et al. (2001) who conducted an ethnographic study of the information needs of technical support workers; and Pettigrew (1999), who conducted an ethnographic study of the information behaviour of attendees at community clinics. All of these studies provided insights that could be used to improve information services, such as information design, and the dissemination or provision of information. It is the view of this researcher that ethnographic investigation of the information behaviour of PI/ HIV/AIDS could generate insights that could inform future health and most especially, HIV/AIDS-related, information interventions.

4.3.4 Potential to study hard to reach and otherwise hidden populations

The potential of ethnographic approaches to explore otherwise hidden, hard to reach or marginalised groups such as men who have sex with men, and commercial sex workers, was particularly important to the current research, which set out to study the information experiences of a stigmatised group of information users. For example, Parker and Ehrhardt's (2001b) comparative analysis of ethnographic methods in HIV/AIDS research and Farmer et al.'s (1996) ethnographic study on women sex workers, demonstrate the potential of ethnographic approaches in studying social and cultural factors associated with increased vulnerability to HIV/AIDS infection among hard to reach, often impoverished communities. This emphasises that ethnographic approaches are particularly important for the current study, which set out to uncover aspects of social reality that might otherwise remain hidden, particularly in settings characterised by extensive stigmatisation, and denial. Arguably ethnographic approaches have provided portraits of the social world of PI/A HIV/AIDS that might otherwise fail to be acknowledged.

4.3.5 Ability to employ a number of research techniques

Ethnography was also adopted because it allowed the researcher to combine techniques such as open-ended and in-depth exploratory interviews, and review of secondary data sources such as HIV/AIDS information packs, leaflets and videos and overt participation. These approaches were helpful in illuminating from different perspectives the dilemmas, complexities, frustrations, routines, relationships, barriers and contextual nature of everyday life in relation to HIV/AIDS-related information.

4.3.6 A flexible research design

Finally, ethnography was selected for the current study because of its capacity for flexible design that evolves contextually in response to lived realities encountered in the field setting. This provides the potential to capture and highlight the importance of a broad range of psychological and information related factors that cannot effectively be discovered using predefined measures and more rigid data gathering procedures. Consistent with this reasoning, Parker and Ehrhardt (2001b) argued that ethnography has been instrumental in capturing and highlighting a range of structural, political, economic and social factors that have increasingly been understood as crucial in shaping the course of the global HIV/AIDS epidemic – but are often difficult to adequately capture or account for in standardised surveys or experimental research designs.

4.4. Quality issues

This section provides a detailed account of quality issues, including ethical concerns, the criticisms advanced against ethnography and how they were addressed in the current study. Validity and reliability issues are also discussed.

4.4.1 Ethical concerns

This section sets out to illustrate why ethical considerations are important in research involving human participants, particularly ethnographic research into very intimate and sensitive issues relating to experiences of people living with HIV/AIDS. Given the stigma and discrimination attached to being diagnosed with HIV, ethical considerations are particularly important in a study involving PLWHA HIV/AIDS. The participants in this study are human beings with problems, concerns and interests that need to be respected. Thus conducting ethnographic research with this group, as Spradley (1979) observed, presented the researcher with ethical dilemmas.

Some of the ethical dilemmas in this study included issues such as whether to audio record what the respondents said or make a written record; how to explain how the data collected will be used; whether to pay informants for participating in ethnographic interviews; and whether to record observations and use quotations in the study.

Consideration of ethical concerns was of prime importance because the practice of interacting with people for long periods of time could give the ethnographer considerable opportunity to learn secrets and intimate details of people's lives. The researcher's proximity to people who may come to accept her as a member of their community could lead to secrets being uncovered or shared. In some instances ethnographers may observe or hear about illegal, dangerous or potentially abusive activities in the course of the field-work. Such information could cause people harm in their communities if it were disclosed (Spradley, 1979; Fatterman, 1983; Chatman, 1992; LeCompte and Schensul, 1999b). The incorporation of these secrets into field-notes and ultimately their presentation in research, presents an ethical dilemma.

The research reported in this thesis demanded careful ethical consideration, particularly of ensuring that participants and communities are protected. Consequently, great care was taken to safeguard the respondents' physical, social and psychological welfare, dignity and privacy.

First and foremost, the researcher sought ethical approval from the Information School in the University of Sheffield by submitting an ethics application which included the following:

- Description of the study and its purpose;
- Description of the population to be studied and of how members of that population were to be selected for the study;
- Description of the research approach and the data generation methods;
- Information about how participants would be informed about the study and what participation will entail;
- A statement assessing the potential risks and benefits of the study to participants and the general population;
- A description of how the researcher intended to protect the identity of participants;
- A statement about dissemination of findings, including a list of journals where articles would be published;
- A statement assuring participants of their right to participate or withdraw without any consequences to them;

- The addresses and telephone numbers of the researcher and responsible people to contact in case of any queries or complaints.

After rigorous review, the research was formally approved according to the University of Sheffield's research ethics policy (<http://www.shef.ac.uk/ris/other/gov-ethics/ethicspolicy>) on 26th of January 2010. Documentation on ethics approval, including the approval letter, consent form and information sheet is included in appendix B. Care was taken to ensure that participants were adequately informed before they gave their consent. Potential volunteers were briefed using an information sheet, which explicitly detailed the purpose of the study, what participation would involve, what would happen in meetings, possible benefits of taking part in the study, how privacy and confidentiality issues were to be observed, and how the results of the research project were to be used. Where necessary the researcher read through the information sheet with respondents who needed clarification about what participation would entail. The researcher also requested respondents to indicate their informed consent by signing a consent form.

In summary, the researcher paid attention to the following ethical issues:

- safeguarding respondents' rights, interests and sensitivities;
- communicating research objectives;
- privacy of respondents;
- fair return; and
- the researcher's safety.

The sections below describe ways in which these ethical concerns were addressed in this study:

4.4.1.1 SAFEGUARDING RESPONDENTS' RIGHTS, INTERESTS AND SENSITIVITIES

Ensuring that the rights and interests of the respondents are not violated by this study was important because ethnographic interviewing, in addition to being a very powerful tool, also has the potential to invade other people's ways of life. It can therefore be used to either affirm their rights, interests and sensitivities, or violate them (Spradley, 1979).

This researcher went beyond merely considering the interests of her respondents and examined the implications of her research for consequences unforeseen by participants. As a way of safeguarding participants from unforeseen consequences, pseudonyms were used

and statements were anonymised. The respondents were also informed that they had the protection of saying things ‘off record’. Such comments were not transcribed.

4.4.1.2 COMMUNICATING RESEARCH OBJECTIVES

The importance of communicating research objectives was highlighted by Spradley (1979), who argued that informants have a right to know the ethnographer’s aim. In view of this, the ethnographer explained to respondents that the aim of her study was to explore the ‘lived HIV/AIDS-related information experience’ of persons infected with, or affected by, HIV/AIDS. This included both positive (e.g. Finding useful information) and negative (e.g. dilemmas and frustrations) experiences of accessing and using information. The researcher also explained that she sought to understand factors that impeded or enhanced the accessing and use of HIV/AIDS-related information with the ultimate goal of helping to mitigate the effects of the disease. The researcher explained that, in addition to accumulating knowledge, her investigation could generate insights that might inform future HIV/AIDS-related information management practice, strategy and policy and potentially help to improve information services for persons affected by HIV/AIDS.

4.4.1.3 PROTECTING THE PRIVACY OF RESPONDENTS

The importance of protecting the privacy and anonymity of informants could not be over-emphasised in the current study, where the main respondents were persons infected with, or affected by, HIV/AIDS. Consequently, all interviews were conducted in private either in offices of the support organisation or in a meeting room in the University of Sheffield’s Information School. The researcher requested permission to use a digital recorder during the interview. The security of the recordings was adhered to by installing encrypting software (True crypt) on the computer and partitioning the hard drive to provide a secure area which could only be accessed by the researcher with the use of a secure log in and password. In addition to employing pseudonyms to places and other identifying features and statements, the researcher also eliminated all names and initials from the transcripts. Only the researcher was involved in the transcription of the data generated during the interviews to maintain strict confidentiality of the respondents.

The back-up copy of the interview transcripts and audio recordings were always locked away in a filing cabinet. Any documents that needed discarding were disposed of as confidential waste.

In summary, the researcher employed pseudonyms, redacted or withheld some biographic data, distinguishing statements, as well as locations, in both the transcripts and the final report, to ensure anonymity of respondents.

4.4.1.4 FAIR RETURN

Ethnographic field-work has, in the past, been criticised on the grounds that the communities studied have benefited little from the studies, while the ethnographers have benefited greatly in terms of publications, research grants and tenured positions in universities and research institutions (LeCompte and Schensul, 1999b; Schensul, 1999). This researcher responded to this criticism by ensuring that the study had practical relevance to the community of PI/A HIV/AIDS.

The research focus was to generate findings which could help to address HIV/AIDS information-related challenges. In so doing, it was hoped that the study could spearhead changes to the circumstances of people affected by HIV/AIDS.

The commitment of the researcher to work for the benefit of the community in relation to HIV/AIDS was also evidenced by the production of two HIV/AIDS sensitisation flyers (see appendix C) aimed at creating HIV/AIDS awareness.

Some respondents appeared to find the opportunity to talk to an interested listener comforting. In most cases, respondents seemed to feel free to tell their whole story – sometimes for the first time.

The researcher also offered her respondents ten pounds (£10) compensation for their time.

A summary of the study's main findings, presented in ways that are readily understood, will be made available to respondents to enable them to understand what the results mean for them and their communities.

4.4.1.5 THE RESEARCHER'S SAFETY

Paying attention to the researcher's safety was also important. This was addressed by planning appropriate meeting places, such as conducting interviews in the meeting room in the Information School and at the HIV support group's premises, dressing formally, and being focused on the research purpose.

Section 4.4.1 has provided an overview of the ethical considerations for the current study. Paying special attention to the ethical issues was of paramount importance in this study, which involved a discussion of very personal and sensitive issues relating to their experiences of living with HIV/AIDS

In section 4.4.2 the researcher addresses the criticisms put forward against ethnographic approaches. She also describes the ways in which she responded to them in order to uphold the quality of the research and its findings.

4.4.2 Criticisms advanced against ethnographic philosophy and methods

In this section, the researcher addresses the criticisms put forward against ethnographic approaches. She also describes the ways in which she responded to them in order to uphold the quality of the research and its findings.

4.4.2.1 ETHNOGRAPHIC APPROACHES LACK BREADTH OF APPLICATION

Ethnographic research has been criticised on the grounds that it does not have much breadth of application (Myers, 1999; Herbert, 2000). Unlike a survey, an ethnographic study typically focuses on a single or very small number of cases in just one organisation or one culture. It seeks to understand and /or generate theories or explanations of how people think and behave that are situated in local time and space. Consequently, ethnography leads to in-depth knowledge of only a particular context and situation. Thus results may only be applicable to that setting (Myers, 1999; Herbert, 2000). Thus, ethnographic research has been criticised on the grounds that it is not scientific because it overly depends on small samples, therefore making it difficult to generalise from an ethnographic study, or to replicate findings.

However, works such as those of Sells et al. (1994) and LeCompte and Schensul (1999b) argued that lack of generalisability does not stand out as a serious limitation of the

methodology because ethnographic research is unique in that the goal is theory development rather than theory testing.

Hence lack of generalisability did not compromise the current study, the goal of which was to generate in-depth knowledge about HIV/AIDS-related information behaviour in order to build a theoretically informed interpretation of the lived information experiences of PI/A HIV/AIDS.

The researcher further responded to the criticism of lack of generalisability of ethnographic findings by seeking to achieve transferability of the findings (LeCompte and Schensul, 1999b; Herbert, 2000). This was achieved by selecting a population of PI/ HIV/AIDS living in England, which could credibly be related to other cases in similar locales. This was consistent with Herbert (2000), who observed that choosing a site that can plausibly stand for other cases (for instance, the dynamics of inner cities, classrooms, college campuses) and demonstrating that the dynamics studied occur elsewhere, could enable ethnographers to avoid criticism of a lack of wider application.

Also there is arguably a trade-off in that, although surveys and census analyses may provide more salient generalisation, they may also be contextually impoverished (Herbert, 2000).

4.4.2.2 ETHNOGRAPHIC APPROACHES ARE SUBJECTIVE

Ethnographic approaches are further criticised for containing a great deal of subjectivity and interpretation on the part of the researcher. This critique is valuable if it pushes ethnographers to spell out the bases upon which they make their interpretive claims.

However, the fundamental irony with this critique is that it fails to recognise that interpretive practices are central to all social sciences and that various social practices structure how data and theory are interrogated to create scientific work. Hence the interpretive dilemma is unavoidable and hardly unique to ethnography. However, the processes of interpretation are still of inescapable importance to ethnographic work, especially where meaning is concerned (Herbert, 2000).

The significance of an event, a comment, or a turn of a head is not always easily explicable by informants. Hence meanings are only revealed in contexts, in actions that transpire and the reactions they inspire.

4.4.2.3 PROBLEMS OF REPRESENTATION

Ethnographers have been criticised for being insufficiently self-conscious about the activities of observation and representation because these activities are neither straightforward nor unproblematic, involving questions of power and bias (Clifford and Marcus, 1986; Marcus and Fisher, 1986; Herbert, 2000) .

These writers observed that a power differential typically exists between the observers and the observed, particularly when the latter belong to a passive, powerless, marginalised or stigmatised, group. For example, Herbert (2000) observed that in the colonial era where the natives were passive and powerless, ethnography could serve, wittingly or not, as a handmaiden to broader colonial projects. As a result, ethnographers could present a version of a social world which is far tidier than what actually exists. These arguments provoke self-examination of the practices and purposes of ethnographic research.

Herbert (2000) observes that, although there is no simple response to this line of criticism, this does not dismiss ethnography per se. Rather, he encourages ethnographers to be self-critical and to interrogate the conditions under which they produce ethnographic knowledge. Herbert (2000) suggests three practices – forthrightness, reflexivity and modesty – that ethnographers can pursue to respond to this line of criticism.

The sections below describe ways in which the above named practices were adhered to in the current study.

Forthrightness

Herbert (2000) argues that it is necessary for ethnographers to be forthright with those whom they study and with the audience of their written work. Although eliminating the power imbalance between the researcher and the individuals being studied is impossible, it is nonetheless essential that the ethnographer explains as clearly as possible the goals and purposes of the project without ever being misleading. The ethnographer should also be honest also with his or her audience (Leo, 1995; Herbert, 2000).

In view of the demands of forthrightness, the researcher explained to the respondents that the aim of the study was to gain an intimate understanding of the daily life experiences of accessing and using HIV/AIDS-related information. They were informed that it was hoped that knowledge generated could inform the development, design and implementation of HIV/AIDS-related information interventions that are sensitive and responsive to their circumstances. The researcher's background as a Ugandan who had been affected by HIV in different ways enabled her to show empathy with the respondents. This helped tremendously to reduce the gap between the respondents and the researcher as they could easily identify with her.

Reflexivity

Herbert (2000) observed that, since ethnographies are as much about the culture of the researcher as they are of the studied, one's position affects one's knowledge and this could negatively influence the ethnographic study. Ethnographers are called upon to be reflexive about how their cultural and intellectual position shapes their appreciation and discussion of data. If some aspect of the social world of the studied group strikes the observer as exotic, it is essential to recognise that this says as much about the cultural setting from which the ethnographer comes as it does the group under observation. This implies that the ethnographer never stands completely outside of either his or her own culture or the culture of the group under study. In contrast, ethnographic effectiveness requires creating a space between the cultures where similarity and differences can be explored and explained in an on-going reflexive process (Herbert, 2000).

Reflexivity was attained through regular reporting of findings in supervisory meetings and conducting member checking with key informants to ensure the report represented the respondents' views and concerns. Ethnography requires that investigators learn from people as informants, rather than regard them as subjects (Spradley, (1979). In this research, during member checking, participants advised the researcher that they preferred to be regarded as respondents, because 'informants' was perceived to have connotations of reporting to the police on criminal activities. This explains why participants in this study are referred to as respondents and not informants.

Modesty

Herbert (2000) suggested that since knowledge is always positioned and partial, ethnographers ought to make honest claims. He argued that the best ethnography improves our understanding of a specific group and enhances our ability to reflect a particular perspective and a particular historical moment. He suggested that ethnographers, like other social scientists, can only hope to add constructively to on-going conversation about the dynamics of social life, hopefully in the most critical and incisive way possible. Herbert (2000) warned that even the best such efforts are partial accounts and thus explanatory claims are kept modest. In order to adhere to the above advice, the researcher was careful to restrict explanatory claims made to those supported directly by evidence, and to make it clear where she went beyond this; for example, generating recommendations for practice, policy and further research.

4.4.2.4 ETHNOGRAPHIC APPROACHES REQUIRE A LONG TIME ENGAGEMENT

Ethnography has been criticised on the grounds that ethnographic studies require more time to conduct, analyse and write up than most other research (Myers, 1999; Hammersley and Atkinson, 2007). Hence ethnographic research is only considered feasible for conducting doctoral studies. However, Myers (1999) observed that although ethnographic research is time-consuming, it is nevertheless a very productive method considering the amount and likely substance of the research findings. Moreover, scholars such as LeCompte (1999b) have suggested that modifications in traditional ethnography provide for conducting compressed ethnographic studies, which accommodate shortened time-lines on occasions where resources of money and time could not permit conducting a more extensive ethnography.

4.4.2.5 SUMMARY

Section 4.4.2 discussed the criticisms advanced against ethnographic approaches and revealed that ethnography is not a flawless methodology. The researcher described ways in which a number of key criticisms advanced against ethnography were responded to in the current study. It is the view of the researcher that the criticisms advanced against ethnography do not diminish the quality of the findings of the current study because the researcher took their admonitions seriously.

4.4.3 Validity and reliability

The current study adhered to quality issues by attempting to ensure that the study results are valid and reliable. This section starts by providing background information including pre- conditions for conducting valid and reliable research. It goes on to illustrate ways in which the current study meets research quality standards.

Reliability and validity are the principal criteria for judging the quality of research. The conventional criteria for reliability and validity derive from positivism and experimental research, where reliability refers to the stability of research results and their ability to be replicated by other researchers. To positivists, validity is a measure both of whether or not researchers have actually discovered what they claim to have found and the extent to which what they have learned can be applied to other populations.

Ethnographers struggle with positivists' criteria for reliability and validity because the methods, field conditions, and objectives of ethnographic research do not lend themselves to the same kind of detachment and control that are possible in clinical, experimental and demographic studies. Consequently, some ethnographers have ignored this epistemological struggle, arguing that rules of validity do not apply to ethnography.

However, other researchers, including Eisenhart and Howe (1992) have argued that different research paradigms require different standards of quality. To complement the positivists' approach to reliability and validity, alternatives more appropriate for ethnography have been devised. These include 'credibility', 'goodness', 'believability', and 'catalytic validity'. On the other hand, scholars such as LeCompte and Goetz (1982) and Schensul (1999) suggested that adopting a middle ground – translating and modifying positivistic rules to make them appropriate for ethnographic practice while attending to the special qualities of ethnographic research and its impact on both researchers and participants – is the most appropriate way of addressing problems of validity and reliability in ethnographic research.

Schensul et al. (1999) observed that ethnography's divergence from the standard canons of validity and reliability maintained in more controlled and standardised research stems from the following:

- ethnography's most important form of data generation is participant observation in which the researchers themselves are the research instrument; and

- ethnographers cannot impose rigid laboratory controls on their studies because their focus is on the natural flow of human events over time.

Nevertheless, the researcher's careful exposition of the field conditions, her actions, including forthrightness, reflexivity, modesty, and methods of data generation and analysis, helped to ensure that the rigour of the findings and value of the knowledge generated were neither compromised nor diminished.

4.4.3.1 TYPES OF VALIDITY

There are several kinds of validity and reliability, all of which affect the extent to which research is judged credible and of high quality. Schensul et al. (1999) defined validity as a measure of both whether or not researchers have discovered what they claim to have found, and the extent to which what they have learnt can be applied to other populations. Thus validity is concerned with accuracy and dependability of research instruments and observations and with the degree to which results obtained by researchers make sense to, and are shared by, people studied and can be generalised to other populations (LeCompte and Goetz, 1982; Krueger, 1988; Schensul et al., 1999).

Internal validity

Internal validity refers to the extent to which scientific observations and measures authentically represent the reality in which the people studied live. Responses obtained from respondents can be a valid reflection of how respondents feel about the degree to which they do (Schensul et al., 1999). Ethnographic studies can achieve high internal validity because ethnographers live with groups for a long time, getting to know people well and allowing for both continuous data analysis and opportunities to refine constructs in ways that ensure a match between scientific categories and participant realities.

Threats to internal validity

An understanding of the potential threats to the internal validity of ethnographic research was vital as far as upholding quality in this study was concerned.

According to Schensul et al. (1999), threats to internal validity might include study scenes not being stable over time as people studied may grow up, die, or move on in the course of

an ethnographic study; participants may withhold information or tell lies while the researcher may omit some components of the population or setting from the study, and /or make premature conclusions. The researcher attempted to reduce the threats in the following ways:

The study was conducted within a specified period of time – March, 2010 to May, 2011 – in order to address the threats posed by mortality.

Threats resulting from respondents withholding information were addressed by building rapport. This researcher worked as a volunteer at the HIV/AIDS support organisation, which increased the degree of trust and comfort that the respondents felt and meant they interacted openly and freely with the researcher. This helped greatly to reduce the observer effect or respondents withholding information or telling lies.

The interviews were arranged in comfortable settings which allowed respondents to freely talk about sensitive and personal experiences of accessing and using HIV/AIDS-related information without fear of inadvertent disclosure. The researcher provided a refund of £10 to demonstrate that respondents' participation was important and valued.

With the knowledge that communities and groups have their own internal dynamics that operate independently of the researcher's presence (which ultimately have an effect on the data generation process), the researcher was careful not to make judgmental or moralistic comments that could potentially make respondents uncomfortable and jeopardise the interview. The researcher kept the interview setting informal and was careful not to use inappropriate or unfamiliar language derived from the researcher's perspective, terminology or jargon derived from theoretical frameworks and concepts, to avoid observer effects that distort the internal validity of data. Consequently, the researcher was able to make sense of the 'lived information experiences' from the consumer's as well as the provider's point of view.

The researcher further attempted to maintain internal validity by guarding her instruments from personal bias through careful execution of the data generation and analysis methods as described in Sections 4.5.

The researcher kept an accurate record of accounts from respondents, including making accurate and timely verbatim transcription of the interviews to make it easy for her to code

and use the data. This was consistent with Hammersley and Atkinson's (1995) observation that meticulous note-taking helps to avoid losing track of important information, providing information that contradicts conventional thinking and convey the richness of the data. The researcher also endeavoured to write up the transcription as soon as possible after the interview and avoided leaving work to pile up. This was in line with Patton (1990) who suggested that the writing up should be done the same day as the interview itself.

The researcher wrote key highlights and made condensed accounts of words and phrases that respondents used during the interview. These were useful for planning future interviews. Attempts were made to document the accounts from respondents through careful digital recording and meticulous verbatim transcription in order to avoid oversimplification, painting a distorted or incomplete picture about her respondents as a result of summarising, restating and condensing. The researcher employed modern technology such as audio recording and used an Olympus DSS Player (transcriber) to enhance the accuracy of recorded events.

Despite being tedious and time-consuming, maintaining an accurate ethnographic record was of tremendous value for the current study. For instance, making a full transcription of all the interviews was beneficial in discovering and describing the main domains and sub-domains in the HIV/AIDS-related information context.

The researcher carried out member checking with ten key respondents to verify correctness of the recorded accounts. This was mainly done through taking the transcribed notes to the respondents to check whether the researcher had correctly presented their issues, and to establish if what had emerged as important issues from the point of view of the researcher were similar to what they perceived as important.

Member checking was further enhanced by key respondents, mainly those that had taken on an HIV/AIDS activist role when they consulted other members of the support group for their views about what had been identified as key issues in the HIV/AIDS-related context. Together these helped the researcher to paint a picture of the world as it actually exists in an HIV/AIDS-related information context.

The researcher responded to threats to internal validity that stem from incomplete representation of the population or selection bias by selecting three segments of the

population, namely: persons infected with HIV/AIDS; persons affected by HIV/AIDS, such as family; and persons with close associations with HIV/AIDS, such as counsellors and support workers. These information-rich cases enabled the researcher to corroborate the data generated.

Thus the researcher attempted to guard against arriving at false, misleading or spurious conclusions, by corroborating results over time, conducting interviews with different categories of respondents so as to check results from each against the other to obtain indigenous explanations in the field setting. This enhanced the validity of the findings as the researcher's observations of events and why they happened corresponded to the respondents' point of view. In this case, the researcher immersed herself in the culture of persons infected with, or affected by, HIV/AIDS over an extended period of time. She built up strong rapport with her respondents which facilitated opening up by the respondents. Participant observation was conducted in a natural setting, thus reflecting the reality of each respondent's life experiences better than contrived, manipulated and quasi-experimental situations would afford.

The researcher therefore obtained rich insights into the information experiences of the respondents and gained an insider's depiction of the studied world. Together these enabled the researcher to generate results which represent the realities of accessing and using information in an HIV/AIDS-related information context.

In an effort to ensure that the results of this study met the high quality standards required of ethnographic research, the researcher ensured she collected a sufficient amount of data during the period of field-work. The researcher only stopped collecting data when further interviews yielded no new concepts. This researcher reached theoretical saturation as described by Charmaz (2006) after conducting 28 interviews; however, she carried on with 12 more interviews to confirm that no new concepts were being generated.

External validity

According to Schensul et al. (1999), external validity addresses both the extent to which results obtained in one study also hold true for other populations, and whether or not theoretical frames, definitions, and research techniques used in one study can be applied by other researchers to comparable studies. They suggest that the claim that ethnographic

studies are so unique that neither their results nor their techniques can be applied anywhere else threatens the scientific value of such studies. Given that the hallmark of good research is the extent to which it increases our knowledge of human life in general rather than just our knowledge of one particular small group, the importance of taking a position that both recognises the uniqueness of the cultures that ethnographers study, and also make it possible for other researchers to make use of their results, cannot be overemphasised.

The researcher attempted to maximise external validity by considering results in the light of other researchers' findings. The researcher conducted a literature review in Chapter two, in order to position the current study within existing research frameworks.

Secondary sources, including HIV education resource training packs, HIV updates and newspapers, fact books, flyers, brochures, websites, healthcare reports, proceedings from HIV/AIDS seminars, workshops and conferences, newspaper articles reporting about HIV/AIDS, and HIV news updates provided by *NAMHIV weekly* (hivweekly@nam.org.uk), were reviewed. Although the data from these sources was not formally analysed, it contributed to the researcher's understanding of the research context in which the study took place.

In addition to generating a rich understanding about the research context, secondary data also helped to corroborate the data generated during participant observation and open-ended, in-depth interviewing.

Consistent with this reasoning are scholars such as Hammersley and Atkinson (1995) and Schensul et al. (1999) who suggested that secondary data sources can potentially enhance the comprehensiveness of data collection and the understanding of the research context. For instance, when respondents complained that newspapers only reported about HIV/AIDS when it had stigma attached to it, this researcher collected the *Metro* newspaper from May 2010 to January 2011 and also read the *New vision* newspaper over the same period, in order to learn about the representation of HIV in popular culture, and confirm if the respondents' concerns were comparable to similar populations in other parts of the UK and other parts of the world. Review of these sources indicated that respondents' concern about negative HIV/AIDS-related reporting was not in any way an exaggeration. It can thus be argued that the review of secondary sources greatly enhanced the quality of this study.

The researcher also attempted to provide detailed description of the research approach she used, including the data generation and analytical methods (see Sections 4.5), to enable researchers wishing to conduct comparable studies with a similar population to do so. It is the view of the researcher that based on her rich description of the setting, the data generation methods, as well as the analytical model that she employed for the current study, she has demonstrated that the research approach could be applied to comparable studies. Descriptions of the terminology and interpretations, definitions of new terminology and an explanation of deviations from common practice were also provided. Together these enhanced the external validity of the current study. It is the view of the researcher that the results generated hold true for PI/A HIV/AIDS including people that have a close association with HIV such as support workers and HIV/AIDS-related counsellors living in the UK and that the research approach used in this study can be applied by other researchers to comparable studies. The detailed research approach supported by detailed evidence in the form of interview extracts arguably provides the richness necessary to support transferability.

4.4.3.2 RELIABILITY IN ETHNOGRAPHIC RESEARCH

According to Schensul et al. (1999), reliability is concerned with whether research results can be replicated. They observed that reliability is a lesser concern in ethnographic research where the intention of the research is to provide exploratory information leading to theory formulation, more valid instrument development and explanation of qualitative results. Nevertheless the researcher ensured that other researchers could approximate her research process by delineating as clearly as possible all the steps she employed in conducting the ethnographic study. This entailed:

- clarifying and describing clearly who the study's key respondents were and the groups they represented;
- providing details of the sampling techniques and research instruments employed;
- making clear how, where and when, observations and in-depth interviews were conducted;
- defining concepts, constructs, domains, and factors clearly, to avoid idiosyncratic interpretation and limited replicability;
- clearly identifying the social contexts and situations of the research; and

- clarifying methods and procedures for analysing ethnographic data so that others can duplicate the work.

Providing sufficient detail (ethnographic accounts) enhanced the reliability of the current study because subsequent researchers can reconstruct the original research approach and analytic strategies.

Although this researcher has provided a detailed account of issues of validity and reliability and how they applied to the current research, she is also aware that there are few really correct answers to any given problem and that there is never a single, completely correct set of procedures for arriving at solutions. This notwithstanding, the researcher arrived at workable and appropriate approaches that stimulated respondents to identify the dilemmas, challenges, connects and disconnects associated with accessing and using HIV/AIDS-related information. The researcher also employed methods and theories that enabled her to identify and explain the patterns of information behaviour within an everyday-life HIV/AIDS-related information context.

4.4.3.3 SUMMARY

In section 4.4 the researcher has attempted to describe the ways in which quality issues were addressed in the current study. She attempted to demonstrate that, despite the limitations of ethnographic approaches, characteristics such as provisions for conducting research in a naturalistic setting, immersion in the research setting and having the potential to study hard to reach populations, rendered ethnography the best research approach for the current study.

In these sections the researcher also attempted to illustrate ways in which pursuing a clear research focus, within a defined research site, with a specified population and time period, building rapport with the gatekeepers and respondents, and meticulous record keeping, enhanced the quality of the current research.

The sections have demonstrated that every attempt was made to ensure that the research is of high quality in that the findings represent the information experiences of PI/A HIV/AIDS. It is the view of the researcher that the research approach for the current study

could be applied to similar populations in other locales. Although the research findings cannot be generalised to other populations, they are potentially transferable.

4.5. Field-work, data generation and analysis

This section discusses the actual fieldwork, including the data generation and analytical methods that were applied to the current study.

4.5.1 Introduction

Section 4.4 discussed ways in which quality issues were addressed in order to uphold the quality of the findings of this study. Section 4.5 is devoted to highlighting how the researcher went about the practical field-work for the current study. The sampling and selection techniques, the study population, access to the research setting, and the data generation methods including the interview process, as well as the data analysis methods are described.

In ethnographic research, 'field-work' refers to the actual research tasks carried out in a field setting or location. Spradley (1979) observed that daily lives are lived in different social situations, dealing with different problems, different things (including various career specialisations, hobbies, clubs service organisations, and different neighbourhoods), all of which represent cultural scenes or fields. Schensul et al. (1999) suggested that a field can consist of institutions, people and their associated activities in a specific geographical space.

An understanding of the field is very important for this ethnographic study because ethnography is very often about studying culture, including subcultures or groups within a setting in an attempt to understand certain aspects of their interaction and behaviour. Consistent with this reasoning is LeCompte and Schensul (1999b), who cited the concept of culture as a lens through which to interpret results as a distinguishing characteristic of ethnographic research.

In the context of ethnographic research, a 'culture' refers to the ensemble of social processes by which meanings are produced, circulated and exchanged (Bow, 2002b). In view of the above, the current study focused on the culture of PI/A HIV/AIDS in Northern England in order to:

- enter their information world;
- achieve intimate familiarity with their lived information experiences;
- carefully generate understanding about their lived information experiences;
- translate that understanding into knowledge that is comprehensible to outsiders who have not experienced the HIV/AIDS-related information world; and
- generate rich insights that could inform the development of HIV/AIDS-related information interventions.

4.5.2 Sampling

Sampling is the process of selecting a few from many in order to carry out empirical research (Pickard, 2007). Mason (2002) also defines sampling and selection as principles and procedures used to identify, choose and gain access to relevant data sources from which to generate data using chosen methods.

Whereas sampling in quantitative research aims at selecting a sample that represents the entire population for purposes of generating generalisable findings, in qualitative research, a case is selected based on what can be learnt from the case, the goal is rarely to make inferences about the wider population based on this discovery (Pickard, 2007).

Hence qualitative researchers engage in sampling for purposes of focusing on specific issues, processes, phenomena and complexity and understanding how these work (Mason, 2002). Time and resource constraints also prohibit qualitative researchers from studying every member of the population (Schensul, 1999; Pickard, 2007).

Although sampling is often associated with a logic derived from general laws of statistics and probability and used for quantitative surveys, sampling and selection, if appropriately conceived and executed, are vital strategic elements of qualitative research (Mason, 2002).

The method of sampling plays a major role in qualitative investigation because the characteristics, composition and scale of the sample give weight to any findings that emerge from the investigation. The sample also helps to tap into appropriate data sources that can provide useful and meaningful contexts, illustrations or scenarios, in order to generate data and ideas which advance understanding and allow the development of an

empirically and theoretically grounded argument. Mason (2002) argues that sampling also links data sources with the wider context.

4.5.2.1 SAMPLING METHODS

The two main sampling methods are probability sampling and purposive or criterion based sampling. Probability sampling is mainly employed in quantitative research and non-probability sampling mainly in qualitative research (Schensul, 1999; Bryman, 2004; Ritchie, 2004a; Pickard, 2007).

Probability sampling techniques (including simple random sampling, stratified random sampling, cluster sampling and quota sampling), are mainly employed in quantitative research to provide a statistical basis for generalising from a research study to a wider population.

Purposive samples are selected because they have particular features or characteristics required for detailed exploration and understanding of the central themes and puzzle which the researcher wishes to study (Mason, 2002; Ritchie and Lewis, 2004; Pickard, 2007).

Purposive sampling is sometimes referred to as strategic sampling. It is so called because it involves selecting groups or categories to study on the basis of their relevance to research questions, theoretical position, analytical framework, and the argument being developed. Hence the logic behind purposive sampling lies in selecting information-rich cases for in-depth study. Purposive sampling could either take the form of *a priori* sampling, where a sampling framework is established before sampling begins; or snowballing, which take an inductive approach to growing the sample as the research progresses (Pickard, 2007).

Pickard (2007) described snowball sampling as a technique that is most commonly used to identify a theoretical sample. Snowballing can either be accomplished through making initial contacts with key informants, who in turn point to information-rich cases; or through beginning with an initial participant who, through the process of interview and observation, will point out characteristics that need further inquiry (Pickard, 2007). In light of the above, this inductive study adopted a purposive snowball sampling technique so as to select information-rich cases for in-depth study.

Snowball sampling was enhanced by selection techniques such as reputational case selection and chain referral case selection (Schensul, 1999). Reputational case selection entailed getting assistance from cultural experts, including people who had lived with HIV for a long time, HIV support workers, and also key gatekeepers to identify suitable people to study. Reputational case selection provided a foundation for chain referral selection where the initial study participants suggested the next person to be contacted. This was a very productive way of recruiting participants for this study.

Snowballing provided the researcher with the opportunity to begin with initial participants whose in-depth interviews and conversations lead to identification of a second group of respondents. Snowballing was suitable for the current study, which set out to yield as much information as possible in order to understand 'lived HIV/AIDS-related information experiences' from the participants' perspective.

Information redundancy was employed to determine when to stop sampling (Lincoln, 1985). Hence termination only occurred when no new information was being added to the inquiry via new interviews.

4.5.2.2 STUDY POPULATION AND SETTING

A 'setting' is defined as a named context (conditions and circumstances) in which phenomena occur that might be studied from any number of angles. A 'case' on the other hand is those phenomena seen from one particular angle. Moreover, a setting may have different cases (Hammersley and Atkinson, 1995).

Hammersley (1995) argued that the choice of a setting plays a significant role in shaping an ethnographic study and advised that settings must be selected in light of their suitability, feasibility and accessibility for carrying out research.

In view of the above, the important considerations for selecting the research setting for the current study included: possible contacts with personnel promising feasible access; the scale of travel costs involved; length of time required to conduct the field-work in the field; and availability of documentary information. Thus the researcher selected an HIV/AIDS support organisation in North England as the most suitable setting for the current study, while PI/A HIV/AIDS and information providers constituted the case.

Hamersley (1995) argues that sampling within cases is very important where cases are not small enough to be subjected to exhaustive investigation. Hence decisions must be made about where to observe and when, who to talk to and what to ask, as well as what to record and how. Although Hamersley (1995) advocates three dimensions of sampling, namely: time, people and context; this researcher selected the people dimension in order to generate understanding and knowledge about lived HIV/AIDS-related information experiences.

Rather than sampling according to gender, race, ethnicity, occupation or educational qualifications, this researcher employed an observer-identified category – persons infected with, or affected by, HIV/AIDS – as well as people with a close association with the disease (Hammersley and Atkinson, 1995).

4.5.2.3 LOCATING THE RESPONDENTS

Spradley (1979) observed that the most persistent problems came from the failure to locate a good informant. According to Spradley, a good informant is one who is thoroughly enculturated, currently involved in the cultural scene, and has adequate time to take part in the study. For the purposes of the current study, respondents were sought who met the following criteria:

- being thoroughly enculturated;
- being currently involved in the cultural scene; and
- being willing to take part in the study.

4.5.2.4 SAMPLE DESCRIPTION

The key respondents in the current study were persons: (a) infected with HIV/AIDS; or (b) affected by HIV/AIDS mainly family; or (c) with a close association with HIV/AIDS – particularly support workers and counsellors.

A purposive sample of 40 information-rich cases in Northern England was selected. As previously explained, the sample size was determined by theoretical saturation – when no new concepts were emerging from further interviews. The respondents knew their culture very well and had expert knowledge and experiences of living with HIV as well as using HIV/AIDS-related information. The sample included a range of age groups, disease stages, sexual orientations, and educational and ethnic backgrounds, including British,

African, and Canadian. Twenty six were people infected with HIV; 6 were affected by HIV in various ways; and 8 were involved in the provision of information and support. Given the need to maintain confidentiality of the participants, further details about them are withheld. The lived information experiences of this group have received little attention from Library and Information Science research.

The group was a rich source of data on what characterises the complex information experiences, including information behaviour and the factors that influence information behaviour, of people directly or indirectly affected by HIV. The group was also a potentially rich source of data on what characterises reactions to an HIV positive diagnosis and living with the disease, including the frustrations, challenges and dilemmas associated with accessing and using HIV/AIDS-related information.

4.5.2.5 SUMMARY

In sub-section 4.5.2, the researcher described the sampling process for the current study and highlighted the rationale for engaging in sampling. The section also discussed the sampling method, the research setting, and the study population, as well as the justification for selection of the research setting and study population. In section 4.5.3 below, the researcher discusses the strategies she employed to gain access to the research setting.

4.5.3 Entering the field

The researcher was conscious that even when cases are carefully selected, they might not be open for study. Hence she developed effective strategies for gaining entry to the research setting. This section describes the process of entry into the field setting, including ways in which relationships conducive to the implementation of ethnographic research were built up.

The research was overt; thus access was negotiated and permission was obtained from the gatekeeper. Access to the research setting was problematic and complicated because the study required access to a vulnerable, stigmatised and sensitive group of information users. This confirmed observations made by scholars such as Hammersley and Atkinson (2007), Mason (2002) and Schensul et al. (1999) that entry into a research setting could be very complex.

4.5.3.1 ESTABLISHING RELATIONSHIPS TO FACILITATE ENTRY

Schensul et al.(1999) and Hammersley and Atkinson (2007) observed that for any ethnographer who is perceived to be an outsider in the research setting, gaining access to a research setting is a complex process, particularly where field researchers are frequently suspected, initially, of being spies, tax inspectors, missionaries, or of belonging to some other group that may be perceived as undesirable. The sections below provide practical considerations surrounding the researcher's relations in the field.

Obtaining official permission

Although some field situations are so open that there are no obvious gatekeepers from whom to obtain permission, focusing on persons infected with, and affected by, HIV was such a sensitive subject that the researcher required formal approval prior to beginning the study (Schensul et al., 1999).

As Schensul et al. (1999) observed, the research setting for the current study required that key stakeholders were identified and formal approval obtained prior to beginning the research. Thus an appointment was booked for 17th March, 2010 for the researcher to meet with the key gatekeeper of the HIV support group to formally request permission to conduct the study with the clients of the support group.

When the appointment was fixed, the researcher sent the approved information sheet, a consent form, a letter of introduction from the University of Sheffield, an abstract of the research and a full research proposal to the key gatekeeper before the meeting date.

On the day of the meeting, the key gatekeeper nearly declined the request to have the study conducted in her organisation because she feared that researcher would breach the confidentiality of the clients. However, the researcher guided her through the approved information sheet which contained full details, including the aim of the research, what participation would involve, what would happen during the interview, the potential advantages of taking part, including safety and confidentiality of the respondents. The researcher's explanation dispelled all the director's fears and permission was granted.

Gaining entry was problematic and complicated. The researcher's experience confirmed Hammersley and Atkinson's (2007) observation that gatekeepers have practical interests

that they and their colleagues are presented in a favourable light as they are understandably concerned about picture of the organisation that the ethnographer will paint. Arguably, in the context of the current study, the gatekeeper sought to safeguard the legitimate interests of the support group and its members.

Introduction to the research site

After obtaining permission to conduct the study, the researcher was introduced to key cultural experts (individuals who have broad knowledge of the research setting), including counsellors and support workers who introduced the researcher to the clients who had come to the lunch club on the 24th March, 2010.

On 26th March, 2010, the researcher received a call from the key gatekeeper, who said that her staff (key informants) had expressed interest in taking part in the study. An appointment was booked and the first two interviews were conducted on 31st March, 2010. This confirmed Schensul et al.'s (1999) observation that when the gatekeepers understand the nature of the project, the reasons for the research and ways in which it will benefit their communities, they can be valuable allies and assets to the study.

As Schensul et al. (1999) argued, the key respondents not only provided knowledge about their lived HIV/AIDS-related information experiences, but also connected the researcher to other possible respondents. After the initial interviews, cultural experts who had already taken part in the research introduced the researcher to clients who came to the HIV support group meetings. The support workers who are also key informants normally said "Have you met Robinah? She is our new volunteer. She is also doing research on the role of information in the fight against HIV/AIDS. Would you at some point like to take part in the study?" The clients' trust in the support workers, and knowing that the support workers had taken part in the study, motivated many of them to take part in the study. This was consistent with Schensul et al. (1999) who observed that, when someone who is well thought of in the community introduces the researcher, this can help to build trust and endorse the research project.

In addition, the researcher deposited printouts of the abstract, information sheet and consent form in the lounge, enabling potential respondents to gain more information about the proposed study.

Some clients initially found it hard to take part in the study until they got to know what actually transpired in the interviews. When their colleagues described the nature of the interview, particularly that the researcher only sought to learn from them what it was like to access and use HIV/AIDS-related information, they then become comfortable with the researcher and took part in the study.

Direct involvement in the research setting

Schensul et al. (1999) advised that once introduced to the site, researchers should maintain visibility through regular visits, informal interviews with people at the site, and willingness to eat meals with them, and attend community events. In the light of the above, the researcher maintained visibility by working as a volunteer at the HIV support group during the lunch clubs, women's groups and school outreach programmes. Voluntary work entailed making and serving tea/coffee and dinner for the clients, washing pots and registering new service users. As people saw the researcher during the lunch club, and the women's group, they ceased to be self-conscious of her presence, and she ceased to be a disturbing element to the clients (LeCompte, 1999; Spradley, 1979).

The interactions with service users, including sitting and chatting with them in the lounge as well as eating dinner with them, participating in social activities, including line dancing, Salsa dancing and doing nails during the women's group pamper evenings, helped the researcher to immerse herself in the research setting, to be an insider, and ultimately build rapport, and gain trust from potential respondents.

Working as a volunteer helped the researcher to function modestly as a member of the cultural scene in a culturally competent manner. Consequently, after two months of voluntary service, the researcher had been introduced to a large number of service users. By that time, fifteen service users had volunteered to share their lived information experiences with her.

Building rapport

Spradley (1979) described rapport as the harmonious interaction between the ethnographer and the informant that facilitates the free flow of information. Thus the researcher's ability to build rapport was another important success factor in ethnographic entry because it not

only facilitated establishing personal relationships in the field built upon trust, but also created an atmosphere where both the researcher and respondents had an interest in the interview. The ethnographer employed her personal characteristics, including social skills, intellectual persistence, commitment to the research project and goodwill in building rapport. This helped her quickly to blend into the research setting.

Inducements including paying the key respondents or cultural experts for the time it takes to participate in an interview, talking about topics of mutual interest as well as sharing their time, transportation, skills, knowledge or other valuable resources with participants could help in building rapport. However, the researcher's experience with the research setting also revealed that personal characteristics such as appearance, background, ease of interaction style, social skills, intellectual persistence, commitment to the research topic and personal goodwill, are invaluable for successful ethnographic entry.

The importance of building rapport in the early stages of the research cannot be over emphasised. Firstly, it helped this researcher to quickly blend into the community, and minimised the degree to which respondents were alarmed or conscious of her presence. Secondly, it reduced the degree to which the researcher disrupted her respondents' normal interactions. This confirmed Schensul et al.'s (1999) observation that the less obtrusive the observer, the more likely the people are to behave as normally as they would.

Making the process of ethnography explicit, and requesting to be allowed to record conversations, conduct interviews and make observations, were also invaluable during the rapport-building and acceptance process. Building rapport is also a very important component in the interview process as described in section 4.5.4.1.

4.5.3.2 SUMMARY

Section 4.5.3 described the strategies the researcher employed to gain entry into the research setting. She demonstrated that entry meant more than going to the field, by describing how she transformed herself into a primary instrument of data generation. This entailed engaging in direct learning through physical and social involvement in the field, observing, and participating in conversations and activities of members of the HIV/AIDS support group. Section 4.5.4 below describes the data generation methods for the study.

4.5.4 Data generation methods

Data generation for the current study is informed by Spradley's (1979) Development Research Sequence although it does not fully adhere to it. Spradley's Development Research Sequence is a qualitative and ethnographic approach that systematically examines a person's experience and its meaning from verbal descriptions. Unlike Spradley (1979), who recommends conducting separate interviews for different kinds of questions such as descriptive, structural, contrast and experience questions, the current study employed all the questions in the same interview as the researcher had no assurance that the same participants would be able to take part in further interviews. In addition, secondary data sources and attending conferences and workshops on HIV/AIDS, were also used to generate data which helped to corroborate the findings from the other data sources.

Ethnographic approaches, particularly participant observation, helped to go beyond the study of external observable behaviour to try to understand individuals from their own point of view. The process will be described in detail below.

4.5.4.1 THE ETHNOGRAPHIC INTERVIEW

The researcher's ultimate goal in conducting ethnographic interviews was to enable respondents to provide a vivid description of their HIV/AIDS-related lived information experiences. Consistent with Spradley (1979), the interviews consisted of a series of friendly conversations, including greeting the respondents, giving explanations about the aim of the research, and requesting respondents to share their HIV/AIDS-related information experience by the use of descriptive and experience questions.

The details of the interview process are presented below.

Preparation for the interview

At the start of every interview the researcher informed the respondent she was a PhD research student from the University of Sheffield. She told them that her research project had received ethical approval and was supervised by Professor N. Ford in the Information School.

The researcher thanked respondents for agreeing to take part in the study and explained that the interview would be an informal chat. She encouraged respondents to talk freely as they would normally talk to a friend or family member. The informal and friendly interactions resulted in a free flow of information and recalling critical incidents.

Consistent with Spradley's (1979) suggestion, at the beginning of each interview the researcher explicitly explained that purpose of the interview was to generate knowledge about HIV/AIDS-related information experiences. She informed them that this knowledge could be used to improve the design and management of HIV/AIDS-related information in order to enhance the impact of information in the prevention and management of HIV/AIDS. She also informed them that the findings would illuminate areas that need special attention as far as the design, organisation, and dissemination of HIV/AIDS-related information was concerned, and provide insights into factors that shape HIV/AIDS-related information behaviour and the effects these may have on the fight against HIV.

The researcher further explained that information from the interview would be incorporated into her final PhD thesis. The researcher also provided a brief explanation about the nature of the interview, and ways in which the respondent's confidentiality and privacy would be protected. She explained that she would protect the respondents' identity by using pseudonyms in both transcripts and field-notes. The researcher also told respondents that she would store the recordings on a password protected and encrypted computer, store the field-notes in a lockable filing cabinet, and anonymise places and statements which could otherwise be used to identify respondents.

The researcher sought permission to audio record the interview and explained that recording would facilitate smooth conversation without the researcher being buried in tedious note taking. The researcher explained that recording would not only help her to better recall what respondents said, but could enable her to go over it later. Finally, the researcher requested the respondents to provide informed consent by signing the consent form.

Starting the interview

In order to break the ice and make her respondents comfortable, the researcher started with appropriate small talk, including asking how they were, how their day was going, and how their family was. For example, small talk about April Fool's Day was a handy ice breaker before starting an interview which was conducted on 1st April, 2010.

The interviews were primarily open-ended and exploratory: those kinds of interviews which focus on expanding the researcher's knowledge of areas about which little is known (Schensul et al., 1999). However, Schensul et al. (1999) noted, that since open-ended exploratory questions give respondents an opportunity to speak about something important to them, they tended to reflect on many topics which may be of great interest to them but of lesser interest for the researcher. This shortcoming was addressed through the use of an interview guide (see appendix D).

As Spradley (1979) observed, ethnographic questions, including descriptive questions, and experience questions, were the main tools employed to unearth lived experiences of PI/A HIV/AIDS. The broad and general descriptive questions allowed respondents to describe their experiences and provided the researcher with a general idea of the respondents' perception of the HIV/AIDS-related information world. The responses to descriptive questions enabled the researcher to discover issues that are important to the respondents.

Critical incident questions were also employed to enable respondents to provide narratives of their experiences. This enabled them to speak from experience about specific incidents or experiences with HIV/AIDS-related information. Respondents were asked to recount specific HIV/AIDS-related experiences of accessing and using HIV/AIDS-related information. Description of the critical incidents enabled the researcher to discover important points about HIV/AIDS-related information behaviour and the factors that shape it.

Conduct of the interviews

The interviews lasted between one and a half and three hours. Thirty seven of the interviews were face-to-face encounters between the researcher and respondents, while 3 interviews were conducted via Skype.

The interviews took the form of an asymmetrical conversation, with the ethnographer asking all the questions and the respondent talking about their experiences with HIV/AIDS-related information. During the interviews, the respondents shared their HIV/AIDS 'lived information experiences' or situations in their own words. According to a number of interviewees, in-depth interviews offered respondents the opportunity to express themselves in a way ordinary life rarely afforded them. As Spradley (1979) observed, the respondents found the in-depth interview an invaluable opportunity to discuss their information experiences and to have someone listen with interest. The interviews also offered the researcher the privilege of having people who are virtually strangers entrust her with a glimpse of their personal lives.

The researcher identified with the respondents by explaining (when appropriate) that her motivation for conducting research on HIV/AIDS was linked to her training as an information professional, as well as her background as a Ugandan who had been affected by HIV in various ways. She told them that 12 members of her family had succumbed to the disease, and two close family members had recently been diagnosed with HIV. She told them that she had experienced a number of challenges, including lack of the information she needed to support her relatives, and economic challenges including paying hospital bills and funeral expenses, as well as taking care of orphans. She told the respondents that her belief was that accurate, reliable and up-to-date information could be a powerful tool in the prevention and management of HIV/AIDS. This was the primary motivation for conducting this study. However, this potential could only be exploited if the information realities of PI/A HIV/AIDS are explicitly articulated.

Together, these enhanced the importance of the research project and greatly helped to build trust during the interview. Immersion and getting genuinely interested in the information experiences of PI/A HIV/AIDS also helped to build rapport and trust. Thus, respondents freely shared their HIV/AIDS-related lived information experiences, including frustrations, challenges and dilemmas that they experienced in accessing and using HIV/AIDS-related information.

During the interview the researcher could pick up a series of terms the respondents had used to describe their information experiences to jog the memory of the respondents to return to the original question and expand on their original description. For example: 'You said HIV/AIDS information is stigmatising. Do you want to tell me a little more about

this?’ Restating underscored the importance of the points the respondents had made and encouraged them to talk more and go into more detail. This was consistent with Spradley’s (1979) suggestion that restating could make the person know that the researcher is listening and show that she is not interpreting their statements from her own perspective.

The researcher attempted to maintain a high quality of interviewing by expressing interest in the respondents, and avoiding offering opinions, making judgments, showing surprise or disgust about what the respondents said. As Schensul et al. (1999) suggested, this resulted in a positive researcher-respondent relationship, which helped to maintain an open flow of communication and allowed respondents to discuss personal, sensitive and sometimes distressing experiences with HIV/AIDS-related information.

At the end of each interview, this researcher wrote down key issues raised in her field-notes. This enabled her to discover questions to ask in future interviews. For instance, stigmatisation related to information was an aspect about which the researcher sought more information in further interviews, because it stood out as an important issue to previous respondents. The researcher reimbursed the informants’ transport costs with ten pounds.

4.5.4.2 PARTICIPANT OBSERVATION

In this study participant observation was conducted between March, 2010 to May, 2011 with PI/A HIV/AIDS support workers, in Northern England. As Bogdewic (1992) observed, participant observation (long term engagement and involvement in the routine activities in the research setting) offered the researcher the opportunity to witness events that outsiders would not be invited to attend. As previously noted, it also enabled the researcher to develop considerable rapport and trust within the research setting and opened more avenues for exploratory, open-ended interviews. Hence the researcher gained intimate appreciation of the dilemmas, frustrations, challenges, ‘connects’ and ‘disconnects’ associated with accessing and using HIV/AIDS-related information. However, the researcher did not include verbatim quotations from field observations in her study because she did not have the informed consent from everyone who attended the HIV/AIDS support group meetings. As well as providing a rich understanding of the research context, participant observation enabled the researcher to tap into the HIV/AIDS-related information world, and to corroborate data generated from individual in-depth interviews; activities which potentially enhanced the quality of the research.

Sub-section 4.5.4 provided a detailed description of data generation methods. Sub-section 4.5.5 below describes the ways in which the data were analysed in order to tell the story about the HIV-related information behaviour of PI/A HIV/AIDS.

4.5.5 Data analysis:

Sub-section 4.5.5 details the methods of data analysis that enabled the researcher to group, organise and classify, or code, data in a systematic way – a process referred to as data analysis (LeCompte and Schensul, 1999b).

Data analysis is a process that enables the ethnographer to turn large volumes of raw data into a manageable form, which can lead to the discovery of patterns and themes in the data, and permits the ethnographer to tell a story about the people or group that is the focus of their research (LeCompte and Schensul, 1999a).

Like all other ethnographers, this researcher generated a large amount of data which consisted of field-notes, interview data and documents. In order to reduce this to a manageable form, painstaking analysis was conducted, involving grouping words together, and organising, classifying or coding them (LeCompte and Schensul, 1999a) in a systematic way. Hence analysis for the current study was a systematic inductive process that clustered together individual items at specific levels into more abstract statements about general characteristics of those items as a group in order to identify issues of importance in the HIV/AIDS-related information context from the point of view of PI/A HIV/AIDS.

Data analysis for the current study is informed by Spradley's (1979) development research sequence although it does not fully adhere to it. Thus it focused on generating understanding about finer, nuanced everyday practical information experiences of PI/A HIV/AIDS rather than the analysing linguistic aspects of the concepts – so as to explore the richness of the data generated. This is a major departure from Spradley's (1979) analytical model which focuses on analysing linguistic symbols created from sounds or physical movements. The sections below provide an overview of the analytical approach.

The interviews were audio-recorded, and transcribed verbatim using an Olympus DSS player. The data were managed and analysed using NVivo 8™, using Spradley's (1979) Domain Analysis.

This analytical approach was applied to the current study because it has been successfully employed in a number of ethnographic studies such as Parfitt's (1996b) study that explored the common experiences of expatriate nurses working in developing countries; Twibell et al.'s (2005) study of faculty perceptions of critical thinking in students in clinical experiences; and Smith et al.'s (1994) ethnographic content analysis of perceptions of couple and therapist perceptions in a reflective team setting.

The analysis was made through four steps adapted from Spradley (1979) and Atkinson and Haj (1996). The researcher maintained the terminology for each of the steps: domain, taxonomic, componential and theme analysis. This method comprised the following stages designed to facilitate the identification of emergent themes:

- identifying key topics, or main domains (domain analysis);
- constructing a taxonomy of sub-categories of the main domains (taxonomic analysis);
- linking the interview data extracts to the categories and sub-categories identified above (componential analysis);and
- identifying relations between main domains and sub-categories, and between these and the whole cultural scene (thematic analysis).

Domain analysis was employed for analysing data because it provided a rigorous analytical approach for systematically identifying patterns within complex data. Although a number of theorists, including Glaser and Strauss (1967), Loftland (1984) and Mishler (1986), offer systematic procedures for facilitating qualitative data analysis that could be feasible for the current study, Spradley's (1979) domain analysis was selected. This was selected because of its potential to provide methodological guidance and facilitate the systematic examination of ethnographic unstructured data to determine its parts, relationships among parts, and their relationship to the whole (Spradley, 1979; Atkinson and Haj, 1996; Gorman and Clayton, 2005).

The approach could also allow the researcher to systematically examine the respondents' experiences in order to translate meanings and to bring to life the experiences of PI/A HIV/AIDS in a way someone unfamiliar with the HIV cultural scene could grasp.

LeCompte (1999a) and Atkinson and Haj (1996) observed that domain analysis could be applied to open-ended interviews and to any source of unstructured data for purposes of enabling researchers to identify issues that are important to participants.

Ethnographic data analysis for the current study began with the first steps in the field – the first field-notes, the first interview and the first experiences. The analysis continued until a fully developed and well supported interpretation emerged. A detailed discussion of the analytical process is given below.

4.5.5.1 STAGE 1: DOMAIN ANALYSIS

Domain analysis is an approach for analysing the content of qualitative data based on the identification of key topics referred to as domains (Spradley, 1979; Atkinson and Haj, 1996; Gorman and Clayton, 2005). Domains refer to categories that include other categories; therefore, domains are classes of objects, things, ideas or events in the real world, or at least in the world as people understand it or perceive it to be (LeCompte and Schensul, 1999a; Gorman and Clayton, 2005). Borgatti (1998) argued that cultural domains are about perceptions rather than preferences; for example, "my favourite foods" is not a cultural domain, but things that are edible is. Members of a domain derive their meaning, in part, from their position in a mutually independent system reflecting the way in which language or culture classifies the relevant conceptual sphere. For example, the

concept 'shape' may have category members such as 'round', 'square', 'rectangular', each of these is a kind of shape and says something different about shape.

The domain structure includes a cover term, an included term, and a semantic relationship. A cover term names the category; included terms are specific examples or names for members of a category. The semantic relationship links the specific included term to the cover term (Spradley, 1979; Gorman and Clayton, 2005). For example, in the current study, 'HIV/AIDS-related information behaviour' is a domain or cover term, while behaviours such as seeking, avoiding, destroying, sharing and hiding information are included terms or members of this category. The semantic relationship that links them is: 'is a Kind of'. Figure 5 gives an example of a domain, included terms and semantic relationship.

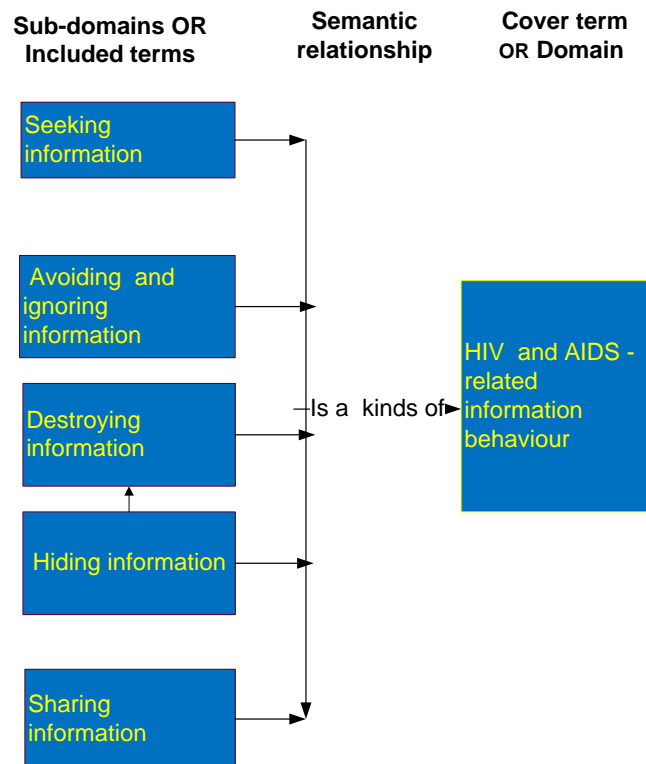


Figure 2: The HIV/AIDS-related information behaviour domain

Spradley (1979) suggested nine semantic relationships that constitute a useful starting point in ethnographic analysis. These are illustrated in Table 3 below:

Table 2: Spradley’s (1979) types of relationships for domain analysis

Type	Relationship of X and Y
Strict inclusion	X is a kind of Y
Spatial	X is a place in Y, and X is part of Y
Cause-effect	X is a result of Y
Rationale	X is a reason for doing Y
Location for action	X is the place for doing Y
Function	X is a used for Y
Means-end	X is a way to do Y
Sequence	X is a step (stage) in Y
Attribution	X is an attribute of Y

Identifying domains

Spradley (1979) argues that shallow domain analysis and the researcher imposing his /her own framework could compromise the quality of results of an ethnographic study. This section illustrates how the domains were identified. It also demonstrates how the researcher attempted to safeguard against shallow domain analysis and imposing her own frameworks. Spradley (1979) argued that identifying and analysing domains is one of the biggest challenges for ethnographers because respondents talk about their experiences in sentences and expressions, with no clues to any relationships: they also often skip from one domain to another. The ethnographer’s background was also cited as a barrier to

discovering domains because some researchers go to the field with a repertoire of analytic domains that are difficult to set aside, which can result in shallow domain analysis.

This researcher attempted to avoid shallow domain analysis and imposition by identifying domains inductively from the interview transcripts and audio recordings from the field-work. Identifying domains entailed reading interview transcripts and listening to audio recordings several times, and listening to conversations during participant observation, in order to identify phrases which expressed concrete issues and ideas as well as the semantic relationships that linked the ideas. The domains were determined directly through the analysis of common phrases and ideas expressed by respondents and by the researcher making appropriate inferences; for example, inferring certain expressions as referring to physical or mental abuse although the respondents had not used the actual word. Domain analysis was repeated as new data was generated from interviews and from participant observation. This inductive process helped to identify phrases, words and expressions describing the lived information experiences, including patterns of information behaviour, in the research data. The qualitative data management software NVivo 8™ was employed to code interview transcripts into phrases or words and to identify a preliminary list of concepts. The tree nodes in NVivo 8™ helped to group together all sub-domains (included terms) within the domain, as well as what the respondents said about each sub-domain. Analysis was a continuous process involving constant review of the material from the field.

It should be noted that data analysis was concerned primarily with generating understanding about finer, nuanced, everyday practical information experiences of PI/A HIV/AIDS rather than analysing the linguistic content. Thus the domains were defined in terms of those incidents, behaviours and statements that stood out because they were crucial, influential and/or occurred often. Domain identification helped the researcher to make sense of what otherwise would be an undifferentiated mass of information (LeCompte and Schensul, 1999b). Rather than merely reflecting the researcher's own pre-defined set of domains, domains were identified from the respondents' statements and experiences.

The sections below illustrate how the statements, phrases and expressions employed by respondents to describe their lived HIV/AIDS-related information experiences, informed the identification of semantic relationships which formed the basis for identifying domains.

Preliminary lists of concepts and emergent domains

Reading the interview transcripts revealed expressions describing various experiences with HIV/AIDS-related information. These expressions were categorised into higher order domains.

One domain contained expressions that the researcher classified as kinds of behaviour toward HIV/AIDS-related information. These included, for example, 'I hide information', 'Taught colleagues about HIV', and 'Stopped accessing information'. Further examples are given in table 3 of appendix E. Hence the cover term, 'HIV/AIDS-related information behaviour' was found to be an appropriately inclusive or general term (domain).

The researcher also discovered various words, phrases and expressions describing the kinds of feelings experienced by respondents after receiving the news of HIV positive diagnosis such as, 'shell shocked', 'world blown apart' and 'ashamed'. Further examples are given in table 4 in appendix E. A review of these feelings described by the respondents resulted in a broader cover term (domain) known as 'post diagnosis reactions of PI/A HIV/AIDS'.

Words, phrases and expressions also described the ways in which other people perceived PI/A HIV/AIDS such as, 'dirty', 'source of contagion', 'dangerous', 'Grim Reaper'. Further examples are given in table 5 in appendix E. An inclusive (cover) term for these perceptions and reactions was identified as "anticipated and/or experienced reactions of other people towards HIV".

Data analysis also revealed a wide range of expressions depicting the respondents' perceptions about the attributes (characteristics) of HIV/AIDS-related information. These included, for example, 'Information is over-scientific', 'I don't understand the medical jargon', 'It is too technical', 'It is above the common person's understanding'. Further examples are given in table 6 in appendix E. Hence the cover terms 'information connects' and 'disconnects' were found to be the most inclusive for this domain.

Statements and expressions also described the channels and sources that PI /A HIV/AIDS consulted for information. These included, for example, ‘read a library book’, ‘got information from booklets’, ‘watched a documentary’, ‘doctor at ‘X’- floor gave me information’. Further examples are given in table 7 in appendix E. Consequently, ‘Sources of information’ was identified as the most inclusive cover term representing the descriptions of sources from which PI/A HIV/AIDS obtained information.

The researcher also identified words, phrases and expressions describing aspects of life about which information was needed. These included, for example ‘basic information about HIV/AIDS’, ‘Meds’ ‘new relationships’. Further examples are given in table 8 in appendix E. Consequently, ‘information needs’ was identified as the most inclusive cover term for these phrases and expressions.

Summary

As Spradley (1979) proposed Domain Analysis facilitated a systematic search for cover terms . A review of the statements, phrases and expressions generated the following broad cover terms or domains (Atkinson, 1995):

- ‘HIV/AIDS-related information behaviour’;
- ‘ Post diagnosis reactions by PI/A HIV/AIDS’;
- ‘Anticipated and/ or experienced reactions of other people towards HIV’;
- ‘Information connects and disconnects’;
- ‘Information sources’; and
- ‘Information needs’.

4.5.5.2 STAGE 2: TAXONOMIC ANALYSIS

Stage two of the analysis – Taxonomic Analysis – is the in-depth study of each cover term (domain) for the purpose of developing a taxonomy of terms associated with the cover term through semantic relationships (Parfitt, 1996b). A taxonomy is defined as a classification system that structures a domain into a flow diagram to help understand the relationships among all terms in the domain (Spradley, 1979; Atkinson and Haj, 1996; Leech and Onwuegbuzie, 2007). Taxonomic analysis was conducted on individual interview transcripts and then combined across respondents in order to discover the

common perceptions within an HIV/AIDS-related information context (Hobbs, 2002; Silverman, 2007). Taxonomic analysis helped to discover sub-domains within each domain and the relationship between sub-domains so as to discover the internal structure of the domains identified in stage 1.

In the current study, taxonomic analysis entailed further in-depth review of the interview transcripts and audio recordings relating to each domain in order to discover the relevant included terms. The researcher listened to the recordings because the transcripts could only provide the details about what was said, but not the tone of the voice and emotion which are equally as important.

Taxonomic analysis allowed the identification of sub-domains to emerge directly from respondent's own words. The sub-domains that emerged arguably represented well the issues and ideas that were most important to respondents. Important issues were identified as those which were consistently raised during in-depth interviews and interaction with clients and in general conversations during support group meetings. This was consistent with Atkinson and Haj (1996) and LeCompte and Schensul (1999), who suggested that in contexts such as public health where the researcher is primarily concerned with practical matters, domains and sub-domains can be defined in terms of concrete issues raised by respondents rather than the linguistic content. They also suggested that events, statements, behaviour or activities could be marked as important because they occur often, are crucial and influential.

For example, taxonomic analysis of the domain 'information behaviour' yielded the sub-domains 'seeking information', 'hiding information', 'destroying information', 'avoiding information' and 'sharing information'. Identifying included terms within domains was an important component of the analytical approach because included terms could provide connotative meaning, and allow readers to develop an appreciation of the meaning of the domain.

4.5.5.3 STAGE 3: SPECIFYING COMPONENTS

When taxonomic analysis was complete, the next step entailed a systematic search for descriptive attributes or components of meaning of elements in each domain. The purpose of conducting componential analysis was to get to grips with what the respondents actually

said about the various domains and sub-domains identified in the first two stages. Hence interview transcripts were reviewed over and over again in order to collate phrases, or whole narratives, on various sub-domains identified in the first two stages (Spradley, 1979; Atkinson and Haj, 1996). This stage was crucial in identifying problems, successes, dilemmas, frustrations, ‘connects’ and disconnects, associated with access to, and use of, HIV/AIDS-related information. As Atkinson and Haj (1996) suggested, the results from this step are typically presented as direct quotations from interviewees, which is how they are presented in the current research.

For example, within the domain, ‘sources of information’ and sub-domain ‘face-to-face information’, the extracts below illustrate the respondents’ perceptions of face-to-face information directly from expert patients as a valuable source of information:

“when I started coming here [HIV support organisation] I started talking to people”. Sarah [Person affected by HIV/AIDS].

My information comes from listening to persons like ***, ***and ***[positive speakers] and *** [support worker]. My understanding has increased phenomenally through that. I hadn’t realised properly until the first time I was with **** [name withheld] and heard him talk that really**** [daughter’s name] could be alive today”. Angela [person affected by HIV/AIDS].

Stages one to three of the analytical approach, which included identifying domains, conducting taxonomic and componential analysis, led to the discovery of parts and their relationships. However, these only represented a skeleton of the HIV/AIDS-related information cultural scene. As such, they could not give an overall picture of the lived information experiences of PI/A HIV/AIDS. In view of this, the researcher embarked on theme analysis in order to build an overall picture of the HIV/AIDS-related information context (Spradley, 1979).

4.5.5.4 STAGE 4: THEME ANALYSIS (RELATING THE DOMAINS AND DISCOVERING THEMES)

Spradley (1997) suggested that ethnographic analysis consisted of a search for the parts of a culture; the relationship among those parts; and the relationship of parts to the whole. In domain, taxonomic and componential analyses, the researcher searched for parts of the HIV/AIDS-related information culture and their relationships. The last stage in the analytical approach – theme analysis – entailed identifying relationships among domains and sub-domains and between these and the wider cultural scene in order to build an

overall picture of the respondents' lived HIV/AIDS-related information experiences, including HIV/AIDS-related information behaviour and the factors that shape it (Spradley, 1979; Atkinson and Haj, 1996; Parfitt, 1996a; Gorman and Clayton, 2005).

Spradley (1979) suggested many strategies that one can employ to undertake theme analysis; for the purposes of analysis for the current study, immersion and selection of organising domains were employed.

Immersion

Immersion entailed participating in the culture, and undertaking an intensive review of the data to identify statements that related one domain and sub-domain to another from quotations made by respondents. This generated insights and enabled relationships to emerge in ways that superficial acquaintance with a cultural scene can never give. In this study, a number of kinds of information behaviours emerged from the data. These include not only seeking and sharing information, but also hiding, destroying, and avoiding information.

Contextual factors helping to determine such information behaviours were also identified. These included not only people's information needs, but also psycho-social reactions described as 'post diagnosis reactions by PI/A HIV/AIDS'; their perceptions of stigma, of mental or physical threat; of others making moral judgments about them, also described as 'Anticipated and or experienced reactions of other people towards HIV/AIDS'; the perceived levels of appropriateness of information, e.g., 'contradictory information'; 'information written at the wrong level', described as information 'disconnects'; as well as the channels and 'sources of HIV/AIDS-related information', also described as 'Information sources'. The examples below illustrate theme analysis.

This quotation illustrates the relationship between anticipated stigma and information avoidance:

"People always hide it [HIV] because they fear the stigma. The stigma also stops people from looking for information. That is why I said that even when we were giving condoms people don't want to come near. They will say 'what are these? You say 'oh HIV information'. They will not touch it. They will go. What they will ask for is condoms ... Not information. No, no, they don't want HIV information. It's only a few who want information".

The effects of information needs on behaviour are illustrated by this interviewee:

“ Research is indicating that at 38 years old, they think my body is probably the age of a 58 year old in terms of the ageing process. So getting more information about that side of things is becoming very important”.

as are the effects of inappropriate (alarming and contradictory) information :

“I stopped accessing information from the Internet because information was being made public too early in the research. A couple of pieces of research were saying one thing and others saying another and I would get upset, very panicky and distressed by that. But then when I went back there was this other research which was saying contradictory information. There is one negative aspect of gathering information from the internet that it is too quickly and readily accessible”.

Organising domains

Identifying organising domains was also employed in theme analysis for the current study. As Spradley (1979) suggested, the strategy entailed identifying a higher level theme and linking other domains to it. Immersion in the research setting, systematic inductive thoughtful process and review of transcripts, enabled the researcher to identify higher level themes (also known as organising domains) that effectively subsumed a number of domains. This analysis resulted in the incorporation of domains identified subsection 4.5.6.1 into 3 broader organising domains. For example, the general theme ‘post diagnosis reactions’ was identified as an organising domain, into which two further domains, namely: ‘post diagnosis reactions by PI/A HIV/AIDS’ and ‘anticipated and or experienced reactions of other people towards HIV/AIDS’ were subsumed. This domain is discussed in Chapter six. Similarly the theme ‘HIV information world’ was the central focus which subsumed two domains: ‘Information ‘connects’ and ‘disconnects’; and ‘Information resources’; which are presented in Chapter seven. The ‘HIV/AIDS-related information behaviour’ theme that is discussed in Chapter five subsumed the ‘information needs’ domain.

In Chapter eight, the last stage of the analytical approach, the researcher went beyond reporting details of events and experiences and attempted to explain how the events and experiences represent complex webs of meaning in an HIV/AIDS-related information context.

4.6. Conclusion

Chapter four described the research approach for the current study. In this chapter the researcher described what she did, why she did it, and how she did it. The researcher demonstrated that ethnography was the most suitable approach because of its advantages, such as the potential to allow in-depth study of the phenomena, and study hard to reach populations, such as persons infected with, or affected by, HIV/AIDS.

The researcher described how she addressed quality issues by paying attention to ethical issues. She also discussed the strategies that were adopted to respond to the critiques of ethnography such as paying attention to the validity and reliability issues of the research. A detailed discussion of the research approach, including sampling methods, respondent description, ethnographic access, together with data generation methods, is given.

The chapter also provides a detailed description of the analytical approach. Spradley's (1979) model of ethnographic analysis, including its application to the current study, is discussed. A detailed description of ways in which the researcher identified domains, constructed taxonomies, identified components and identified relationships between domains and sub-domain in order to build the overall picture of HIV/AIDS-related information context, is provided. The analytical approach, including domain analysis, taxonomic analysis, componential analysis, as well as theme analysis, enabled the researcher to identify threads of meaning and constituted critical step leading to the final stages of the research. This provided the basis for making interpretations and suggesting as well as implications for practice, strategy and policy. Therefore it has laid a solid foundation for Chapters five, six and seven, which consist of the detailed analysis of the data; Chapter eight, which consists of the interpretation of the results; and Chapter nine, which discusses the conclusions, key findings, highlights the implications of the study, and suggests future research.

CHAPTER 5- RESULTS PART 1: HIV/AIDS-RELATED INFORMATION BEHAVIOUR

5.1. Introduction

Chapter four provided a detailed description of the research approach for the current study. Section 4.5 presented a description of how field-work, data generation and data analysis were undertaken for the current study. Sub-section 4.5.5 described the analytical methods which facilitated a systematic search for cover terms or domains as presented in sub-section 4.5.5.1. Hence Chapter four provided a framework for presenting the results in Chapters five, six, seven and eight.

The results are presented in three main parts in Chapters five, six, and seven, which represent the pre-theoretical (Wilson, 1999b), or vertical modelling stage (LeCompte and Schensul, 1999a), in which the researcher tells the story about the ‘lived information experiences’ of persons infected with, or affected by, HIV/AIDS (PI/A HIV/AIDS). The interpretation of results is embarked on in Chapter eight, which brings together the results presented in Parts 1-3, and illustrates how they interact to shape HIV/AIDS-related information behaviour.

Chapter five – the first part of the results – presents HIV/AIDS-related information behaviour, such as hiding, seeking, avoiding, sharing and destroying information which emerged from data. A small number of quotations, which illustrate ideas, actions, and events as understood, perceived and experienced by PI/A HIV/AIDS, are selected to illustrate patterns of information behaviour. These constitute the evidence to support the findings, and to indicate to the reader what it means to access and use information in the face of a life-threatening and stigmatising health condition, that is, HIV/AIDS. Thus the findings consist of a description of the domains, and a taxonomy of sub-domains developed from the analysis of what respondents actually said within specific sub-domains.

In the context of this study, HIV/AIDS-related behaviour refers to ways in which persons interact with, relate to, and use information for the prevention and management of HIV. The analysis of data revealed that PI/A HIV/AIDS engaged in a wide range of information

behaviours in the journey of living with an HIV/AIDS-positive diagnosis. These included not only seeking and sharing information, but also behaviours such as hiding information, destroying information and avoiding information.

In Sections 5.2-5.6, the researcher employs the respondents' own words to highlight the patterns of HIV/AIDS-related information behaviour. The researcher concludes this chapter by arguing that understanding this behaviour could potentially enhance HIV/AIDS-related information service design, management, and provision, for the purpose of mitigating HIV/AIDS

5.2. HIV/AIDS-related information sharing

Sharing HIV/AIDS-related information was a double-edged sword because, in some instances, it attracted support from family, friends, medical practitioners and colleagues at work; however, in other cases it resulted in undesirable outcomes such as discrimination, isolation or desertion, as well as physical and verbal abuse. Consequently, sharing HIV/AIDS-related information was predominantly undertaken by HIV/AIDS activists who were no longer afraid of the negative effects of sharing HIV/AIDS-related information. In the context of this study, information sharing refers to giving, receiving and exchanging information for purposes of teaching and learning about HIV/AIDS. Hence, information sharing refers to planned, as well as unintentional, endeavours to disseminate and exchange HIV/AIDS-related information. This definition emerged from the data, which revealed that PI/A HIV/AIDS, as well as HIV support workers, predominantly engaged in informal and incidental information sharing.

The main avenues of sharing HIV/AIDS-related information that emerged from the data include:

- Sharing information during social interactions;
- Sharing information with family and friends;
- Sharing information using life stories;
- Information sharing through school outreach programmes;
- Taking information to the people;
- Information sharing through public discourse;
- Conducting HIV awareness training sessions.

Sub-sections 5.2.1-5.2.7 illustrate HIV/AIDS-related information sharing experiences.

5.2.1 Sharing information in social contexts (during social interactions)

The data revealed that PI/A HIV/AIDS were comfortable sharing information during social interactions, such as meetings that were exclusively with other PI/A HIV/AIDS. They reported that they were confident to share HIV/AIDS-related information because they could identify with other people who were experiencing similar circumstances as themselves. The quotes below illustrate information sharing during HIV/AIDS support group meetings:

“...the fact that there are other people out there living the same life that I am living, and being able to talk to those people and to interact with them. And swap stories because you can all feel that you identify with each other. So the information passed out might not be serious medical information, it might be stories such as I went to hospital and this happened, things that knock you all together and you don't feel you are the only one”. Joel [person infected with HIV];

“....going to [...name of HIV support group], seeing a lot of people who tell you that ‘I was diagnosed in the early 80s’; there are some people who have been living with this illness for 20 years. When we came here we saw people who were in wheelchairs but now they are walking, they are doing everything by themselves. It's like, if they manage why not me”. Andrea [person infected with HIV];

as well as during seminars and conferences:

“...when we went to the conference in Leicester and the hall was full of HIV people from all over the world... Another lady stood there and said she was a doctor but she was HIV-positive. That is when I stopped worrying. And some told us when they were diagnosed, and that they were still carrying on taking their medication. And that is when we started learning that you should not skip your medication that is the main point. you should not take any other tablets Don't just buy tablets over the counter and take them before you tell your doctor”. Rose [person infected with HIV].

Social contexts were a vital avenue of sharing HIV/AIDS-related information. Forums such as conferences, seminars and HIV support groups promoted HIV/AIDS-related information sharing because people had no fear of being judged or discriminated against. Talking to other PI/A HIV/AIDS was a source of reassurance that life was worth living.

5.2.2 Sharing information with family and friends

Sharing information with family and friends entailed holding informal discussions and sharing information resources. For instance, Sarah [person affected by HIV] who shared information with her dad, reported that:

“he goes to one source and I go to another and we come back and share our information, and that often reveals a bigger picture. [...] We are able to talk about it as a family; if I read something we can discuss it. So whenever I got treatment updates I would take them home, and he already has things like the Health Service Journal and things like that, so we see all kinds of publications”.

Respondents shared information with family and friends to dispel myths and unnecessary fears surrounding HIV. The extracts from persons infected with HIV below illustrate this:

“ my daughter [...] went for dinner at my sister’s house [who is HIV positive] and my sister drank from a cup with a straw, and she came and said ‘mom, can you catch HIV from a straw?’ I said ‘No you can’t’. So I had to teach her”. Jane [person infected with HIV];

“...someone asked ‘Can we get HIV through sharing forks?’ I had the opportunity to say that you can’t catch it through kissing, toilet seats, and sharing utensils. I try to educate people that there is treatment available; I train them that people with HIV are just like any other people”. Julius [person infected with HIV];

“When I was diagnosed, there was a piece of paper and I actually saved this paper. There were potentially 144,000 people in [name of city] alone. I showed her [daughter] this paper and said ‘I am not the only one’; I said ‘Stop worrying, and there is treatment, ongoing treatment. Stop worrying about my [emphasis] status. Stop worrying about your children’s status.’” Jo [person infected with HIV].

The findings of this study revealed that sharing HIV/AIDS-related information not only facilitated learning about HIV and managing the illness, but also helped to clear unnecessary fears surrounding HIV. Information sharing also resulted in improved quality of life of PI/A HIV/AIDS because they received support from family and friends.

This notwithstanding, the data revealed that sharing HIV/AIDS-related information was not without problems. It was reported that, in some instances, sharing HIV/AIDS-related information resulted in negative effects such as isolation and desertion:

“I don’t see her anymore. She was the best, the best of the best, the best in the world; every Thursday we used to have tea at my house, but now she can’t come near me. No”. Belinda [person infected with HIV];

“I had not told that lady that I am positive and [name] told that lady that I am positive. She never called me again. She stopped calling me when she was told I am positive”. Fiona [person infected with HIV].

It can be said that information sharing not only helped to provide basic HIV/AIDS-related information; it was also a means of providing emotional, medical and social support. It is important to note, however, that sharing HIV/AIDS-related information was in other instances problematic, and people resorted to concealing information to avoid discrimination, desertion, physical and mental abuse. Hence sharing information was a double-edged sword, because it could be beneficial for providing/getting support, but it could also be harmful, depending on how the person with whom the information was shared responded.

5.2.3 Sharing information using life stories

The findings indicate that PI/A HIV/AIDS shared life stories to create awareness about HIV/AIDS. Life stories were cited as an invaluable source of encouragement, particularly for people who were newly diagnosed with HIV, or members of a family whose relatives had been diagnosed with HIV. Life stories consisting of success stories, portraying persons infected with HIV/AIDS in a positive light such as recovery from illness, progress

in their careers, or having a happy family life, provided assurance that an HIV diagnosis was not the end of the world.

For example, Justus [person infected with HIV] reported his information sharing experience:

“ when they meet someone like me who has lived with HIV for 21 years, who can tell them that my CD4 count was four (4) and I recovered, I am living a normal life, I have a job, they get a lot of encouragement. Like the lady upstairs, she is scared of everything; you know she was crying the first time we met. She said no, there is no hope; I said get over it, you can live. ”

Loy’s [person affected by HIV] information experience illustrates the value of information sharing through life stories:

“When my mom was diagnosed with HIV I did not have information about HIV/AIDS. I invited a man who I had watched on television teaching about HIV to talk to my mom who had given up on life. That man had lived with HIV for 15 years. He reassured my mom that she would be ok if she took her medication. He taught her the importance of taking medication, eating regular meals and avoiding stress. He told her that she did not have to feel ashamed, because HIV is like any other illness. This was the only person who calmed my mom down and brought a ray of hope in her life. He also sold us booklets about care, nutrition and medication, to enable us to learn more about HIV”.

Life stories were also invaluable as far as reducing HIV/AIDS-related prejudice and stigma was concerned. For example, Angela [person affected by HIV] uses her daughter’s death to teach others and create awareness about HIV/AIDS:

“ ... I like the fact that I just say it, um because I see it as a way of confronting people with their own prejudices and make them think: ‘Oh gosh, this woman is prepared to talk about it, now it is my chance to listen, to ask a question, to try and understand more, to think about my own prejudices.’ I am not by any means unique, but I might say my personal experience and my personal story might be unique. They are all unique, because this was a young heterosexual woman dying without being formally diagnosed. I don’t want people to feel sorry for me, I want them to say: ‘Oh my God, I don’t want that to happen to me or my family.’”

Life stories are very important in creating awareness about HIV, particularly in places where people lack knowledge about HIV/AIDS. The tendency for people to identify with the story-teller makes learning about HIV/AIDS more relevant. This notwithstanding, the data revealed that there were some isolated cases of resentment and ridicule resulting from sharing life stories. For example, Job [person infected with HIV] reported that one of the

pupils who listened to his life story called him a ‘butt boy’ [slang for gay man], while a teacher asked him if HIV/AIDS could become airborne.

5.2.4 Information sharing through public discourse

HIV activists, who had made their HIV status public, shared information with larger audiences by engaging in public discourse. Some people participated in interviews:

“I went on Radio [Name withheld], I approached them, told them who I am, and offered to be interviewed on radio regarding HIV/AIDS. Because I had come from [name withheld] where people talked freely about HIV, and where everybody had HIV, I could talk about it freely. Yet here [England] it is so different, so I went to the radio station and said: ‘This is who I am, I have been living with HIV for 21 years, and it’s time someone who has HIV had dialogue with people out there.’” Ben [person infected with HIV].

Others wrote down their life stories for publication in HIV/AIDS magazines:

“...There is a magazine where my story was published [...] I wrote the story including what HIV is, and routes of transmission”. Justus [Information provider];

“I participated in a photoshoot for [publication] in the issue of [date]. I was interviewed about a number of issues to do with HIV”. Joab [person infected with HIV];

while others conducted training sessions on basic HIV-related information such as routes of transmission, medication and side-effects:

“We do a number of presentations...three or four-hour presentation and tell people everything they possibly want to know about HIV. We do these presentations so that health professionals and social workers will have enough information; if they come across someone who is HIV-positive they will have the right information. ...We always say that HIV is an equal opportunistic infection. ...We cover everything from simple things like, what is HIV? That it is a virus, and what HIV/AIDS stands for, how it is tested for, the medication available, the side-effects of medication, how it is transmitted. We do routes of transmission exercise and ask people to identify routes of HIV transmission by looking at pictures on cards. We try and dispel as many as myths as possible., and give them non-technical information, non-medical information, so that they do not have misguided ideas”. Jack [information provider].

Although sharing information through public discourse was an effective way of creating awareness about HIV/AIDS, it was predominantly spontaneous as it was carried out on a voluntary basis. Consequently, only a very small proportion of the population could be

reached, as people had to find time outside their normal work schedules (such as during annual leave) in order to engage in sharing HIV/AIDS-related information. Interventions to ensure sustainable dissemination of HIV/AIDS-related information are urgently required.

5.2.5 Information sharing through school outreach programmes

HIV-positive speakers employed practical teaching techniques such as life stories, personal experiences, visual aids such as showing photographs of deceased children, and other practical demonstrations to provide information about HIV/AIDS to 15 and 16 year olds in schools. School outreach sessions were conducted in ways which made the learning about HIV/AIDS relevant:

“We have clients, HIV- positive speakers that do go out into schools and give talks about themselves as living with HIV. It is the inter-link with O an actual person; this is not a picture, he is a real person, and that way it clicks in a bit. You get that interaction from saying things such as: ‘Oh, by the way, I was diagnosed at such and such a time, I was given two weeks to live’ ... it clicks much better than reading it in a book”. Luke [information provider].

HIV-positive speakers employed real life stories to teach young people about the dangers of taking risks. For example, Angela [person affected by HIV] used the picture of her beautiful daughter who died of AIDS:

“...the important message ...in relation to ****’s [daughter’s name withheld] death is ‘do not have un-protected sex because you will be putting yourself at risk’. Statistically you are about to come into the age group where you are going to be at risk, do not[emphasis] put yourself at risk. I tell them a story so that they see it; so that they listen and see it as relevant. I use dramatic techniques; I challenge, teach, entertain, and I think information delivery should combine all those because you are in the business of persuading; it’s all about persuasion”.

Job [person infected with HIV] used his circumstances to emphasise the importance of avoiding taking risks:

“I have talked to 1000s and 1000s of young people and you could hear a pin drop literally, they are attentive and listening because they ask relevant questions. We talk to 13- and 14-year olds all the way up to university. I think, for me, my experience talking to young people face-to-face is very, very powerful. I know this from talking to young people; I know this from talking to teachers, and I know this from reading the reports that we get back as an organization”.

Positive speakers also used personal stories to share basic information on HIV, particularly HIV transmission:

“...we are in schools as well, so we talk to 15- and 16-year olds. We basically talk about our life stories, about the disease, how not to catch the disease, the benefits of being tested. Basically I show them myself and tell them listen, had I got the therapy earlier on, I would still have both my legs, you can avoid this; I would still have both my eyes, you can avoid this. My HIV took my knees away and I can never have a proper immune system. We explain to them that you can take a test any time before you get into that danger zone below 200 CD4; you can have a full immune system, you can plan a life, you can plan to have children, you can have a career, you can buy a car”. Ben [person infected with HIV];

“...we have been very influential because we go to talk to teachers, and then we go to continuous professional development sessions with Personal, Social and Health Education (PSHE) teachers. The last time I did it was three months ago, there were 40 teachers”. James [information provider].

Sharing HIV/AIDS-related information in a school setting was vital, as it targeted young people at an early stage. Teaching young people about HIV was beneficial because this is a time in life where things can go wrong if people do not have the information to enable them make informed choices and decisions. Hence, the practical demonstrations of the dangers of living with undiagnosed and untreated HIV, as well as the dangers of taking risks, provided vital lessons to young people. Although school outreach sessions were vital in disseminating HIV/AIDS-related information to young people and teachers, the sustainability of such sessions remains a major challenge because they are run on a voluntary basis; hence, few schools could be reached. There is a need for interventions to ensure sustainability of school outreach sessions.

5.2.6 Taking information to the people

In addition to conducting outreach sessions in schools, and providing information to people who came to the support group meetings, the HIV/AIDS support organisation also provided information by going out to meet people who felt uncomfortable with coming to HIV support group meetings. This entailed mounting information stands in hospitals:

“...we give out booklets. We do information stands at conferences, that is mostly where we provide our service”. Claire [information provider];

“at the information stands you give out information to people. ” Luke [information provider];

“...we go out to hospitals because we understand that, at the end of the day, not everybody wants to walk into a centre for HIV necessarily. That is why [Name] goes to the GUM clinic, on the ‘X’ floor and he is their out-reach there. So, to be honest, we have learnt to go out to them where they might need us”. Rita [information provider].

Or conducting meetings away from HIV support organisations and making telephone calls to people who felt uncomfortable being seen at the HIV/AIDS support group premises.

“We have some clients where we only speak on the ‘phone; we have other clients where we meet them in Meadow hall, or we will meet in another part of town. The reason is that we have to accommodate client’s needs, and if they don’t want to come and get information or support here, we go to them”. Claire [information provider].

The results revealed that some people felt uncomfortable coming to the HIV support group meetings; hence strategies, such as meeting people away from the HIV support organisation, posting resource materials in opaque plastic bags, as well as holding telephone conversations, were vital avenues of disseminating HIV/AIDS-related information to such people.

5.2.7 Conducting HIV awareness training sessions

Training sessions for specific groups of people, such as General Practitioners and home-based care workers, provided an important avenue of sharing HIV/AIDS-related information. The training sessions equipped professionals with basic HIV/AIDS-related information to enable them to work comfortably.

“...we have been funded a small amount to deliver awareness sessions to GPs in [Name of place]. The reason being that you can send out the information they need, but you need real people to train them, like Justus to tell a story- that kind of thing”. Rita [information provider];

“...courses that we are doing now through [Name of city] council; they are called ‘adult neighbourhood training’, so basically people who come to see us are home health-care workers. These people were finding out that more and more they had to go to the house of someone who has HIV/AIDS. They were scared to go there because, for all they knew, if I share a glass with you I may catch it and die. So the health-care workers were saying ‘I am not going to do it’. So we [Name of HIV support organisation] were commissioned to speak to 500 of these care workers in [Name of city] and explain to them the basics of HIV so that they are more comfortable when they do their work”. Justus [information provider].

Training sessions were particularly vital for home-based care support workers and medical practitioners whose jobs had become so difficult because they were afraid of contracting HIV from patients. The findings revealed that training sessions potentially demystified HIV, and reassured health service workers that it was safe to work with persons infected with HIV if they applied the normal safety standards.

This research has identified the avenues of information sharing, namely: sharing information during social interactions; sharing information through life stories; sharing information through school outreach programmes; taking information to the people; information sharing through public discourse; and conducting HIV awareness training sessions.

The benefits accruing from sharing HIV/AIDS-related information, such as: providing basic facts and dispelling myths about HIV; encouraging colleagues diagnosed with HIV; confronting apathy, stigma and prejudice; and educating people on ways to safeguard themselves from contracting HIV; have been highlighted. The negative effects of sharing HIV/AIDS-related information, including discrimination, isolation and desertion, were also discussed. Consequently, sharing HIV-related information was described as holding a double-edged sword.

Although the information sharing experiences were invaluable as far as the prevention and management of HIV/AIDS is concerned, most of the efforts cited were on a very small scale and on a voluntary basis, which raised issues of sustainability. This is only a drop in the ocean since volunteers can only do so much. Interventions in terms of HIV/AIDS awareness are urgently needed.

5.3. HIV/AIDS related information need and information seeking

In the context of this research, ‘seeking information’ means the information seeking activities that PI/A /HIV/AIDS, were engaged in. This section described information seeking activities in response to the complex information needs which arose specifically from being infected with, or affected by, HIV/AIDS:

5.3.1 Seeking information to learn about HIV transmission

For example, Angela [person affected by HIV/AIDS] sought information to understand how HIV is transmitted:

“...What I did do after a while following [the death of my daughter], I found a book called Vamps, Victims and Virgins which was all about women who are HIV positive. ... And I started and read that because I wanted to understand more about how it could be transmitted. After a year, I was curious to find out what the disease was”.

“The only information I sought was more about safe sex, how not to pass it on”. Ben [person infected with HIV];

“...it is very important for people to know how the virus is transmitted so they do not go about infecting others. As a positive person, that has always been my fear – passing the virus on to someone else”. Justus [information provider].

Sarah [person affected by HIV] also sought for information to learn about HIV:

“when I first found out [that dad is HIV-positive] I would probably just type in Google: ‘HIV’; when you know the actual experience of living with it, it is obviously much wider than this one term. You know this is the case because so many booklets exist for different things such as: HIV your viral load; HIV and lipodistrophy; HIV in women; HIV in children; HIV and sex; and things like that. The fact that they all exist demonstrates that HIV is not just one big thing; you know, that was the biggest revelation for me when I started looking for information. You tend to reduce it to these three letters, [HIV] but you don’t think about the many ways it manifests itself”.

In the quest to learn about HIV, some people engaged in hysterical information seeking (hysterical information seeking in the context of this study refers to the kind of information seeking undertaken by people experiencing extreme emotional distress, anxiety and shock) because they wanted to know all there is to know about HIV/AIDS in the shortest time possible. Consequently, they overloaded themselves with information and ended up being

panicky. This was particularly true for people who had no previous knowledge about HIV when they were diagnosed:

“They want to know everything and that is not gonna help. What is gonna help is to take information step by step about what they need to know and asking the right people. For instance, you have situations where partners found out that their loved one is positive and they go out and they scare themselves about what is gonna happen to the loved one”. Rita [information provider].

Sarah [person affected by HIV] also reported that:

“..I really wanted to know everything as soon as possible. I know now that you will always need to learn because we are still learning about the disease; but at that time, you wanted to know everything you could about it in the space of five minutes”.

The above quotations reveal that seeking HIV/AIDS-related information is important for persons infected with, or affected by, HIV because it enabled them to gain an understanding of the disease. The data also revealed that, although some people experienced a period of denial and wanted no information after diagnosis, other people wanted to know as much as possible shortly after the diagnosis or bereavement. These findings highlight the importance of knowing that this is not a homogeneous group of users, and it is necessary to consider user’s circumstances for effective and efficient HIV information dissemination.

5.3.2 Seeking information for legal purposes

The findings indicated that HIV/AIDS-related information was not only sought to generate knowledge about the illness, but information was also sought to support legal procedures. For example, Justus [information provider] and Fiona [person infected with HIV], who looked for information for immigration, purposes, reported that:

“.....I am smart enough to search and get information. You know there was a couple, they were seeking asylum here, and they wanted to deport them, so we gathered information about what life is like in Zimbabwe if he goes back, about the medications he was on today, and that he was on the wrong side with Mugabe. If he went back to Zimbabwe, he would have medication that is ten years older than what he is taking now, which is not good. We gathered all this information together and passed it to his lawyers; they called me to testify in court, so we fought his immigration case for him”.

“ the information I looked for is for my solicitor on what they are saying about HIV in Kenya. Because of my papers, I looked at information about HIV in Kenya so that I can give it to my solicitor. What is happening in Kenya, how people are doing, and the medication that is being taken in Kenya? I looked at information about the day-to-day life of HIV-positive people in Kenya. Whether it is easy to access medication or not, and whether hospitals are near my home area or not. I looked for all that information and provided it to my solicitor”.

5.3.3 Seeking information for career-related and social reasons

The analysis of the data revealed Information was also sought to clarify the implications of being HIV-positive on people’s career prospects. For example, Monica and Job [persons infected with HIV/AIDS], respectively reported that:

“...so to ease my worries I went to hospital. There are health advisors, they are well informed and they know all the new information coming up about HIV. The person I asked talked to me and said it should not affect you because HIV is a very weak virus that can even be killed by soap or alcohol... She had information for me about that that she gave me; I went home and read it. It was so calming so soothing. Since then I have done my course, and I have never looked back”.

“.... I had to contact occupational health, and speak to them about what my status meant. Whether I could actually practice as a psychiatric nurse because I didn’t know what implications it has. I knew that with some jobs, you were not able to work as an HIV-positive patient”.

Respondents also sought for information relating to their social life, particularly information that would help them begin new relationships and disclose their HIV status to prospective partners, family, friends and the wider community:

“Even now I have guy who is interested in me, but you can’t just tell him because you don’t know the implications of telling him. I am dodging him in many ways, and he is trying many ways to get me. [Pause] Maybe you can tell me how to handle such a case. I need information on how to handle that. Maybe there are ways of disclosing negative information. I need to know a good way to enable me to disclose it, and that is a gap in my knowledge. Of course I need information on how I can put it across. I wanted to know how I will tell my parents. It is something very important; I wanted to know how. I am still thinking about how to tell my son. It is still a question of how I can tell my son about it. Because I haven’t told him yet and my son needs to know; he is 20 years old. And again, how would I inform my partner. That I don’t know. Maybe you can help me with that. How I would tell him, because I prefer not to mention anything to my friends”. Fiona [person infected with HIV];

“I needed to know who I needed to tell, did I have to tell everybody? I was having my foot done, and I called the clinic because I couldn’t talk to anybody. I had got something wrong with my foot and I had to see a chiroprapist; I would see him every three months. Now I didn’t know whether I had to tell him or not. Because he is cutting my skin off my foot, I didn’t know whether he could get it [HIV] or not. But now I know he can’t. But I had to make sure that I was not getting myself in trouble in case he might get it. When I phoned the clinic they said that you don’t have to tell anybody”. Jane [person infected with HIV].

To summarise: respondents who feared that an HIV diagnosis would stop them from pursuing their career, starting new relationships, or affect their immigration status, sought for information to clarify those issues. Issues to do with disclosure constituted a major paradox because, while respondents did not want to inadvertently pass on HIV, they could risk making their HIV status public if they disclosed it. The need to maintain privacy and avoid passing on HIV could result in a number of forms of information behaviour, as will be discussed in detail in Chapter eight. Chapter nine will discuss ways in which accurate and reliable information could go a long way to reducing anxiety and the uncertainties surrounding socio-economic aspects in the lives of PI/A HIV/AIDS.

5.3.4 Biomedical information

Other areas, where information was sought, pertain to HIV/AIDS medication, including available options, and what taking medication could entail:

“...the most important information I needed was around ah combination therapy. I was diagnosed eleven years ago, and from being diagnosed, I wanted to start triple combination therapy. So for me, the most important information that I needed on that day was about medication that I was going to be taking, what side-effects the medication was going to have on me. I mean, for me I think the first four or five years of my information needs about HIV were predominantly medical”. Job [person infected with HIV];

“I didn’t want to start the meds. And my friend says to me: ‘Well, I don’t understand this thing about meds’. I needed to know what the meds are gonna do I wanted to know what they are gonna make me feel like; I have got to take care of my daughter, I don’t want to start medication and like I can’t look after her. I wouldn’t take the pill unless I knew all about that pill and all that it is going to do to me. I smoke weeds, would they have an effect on weeds; I have known people who take street drugs and then their meds and they can kill them, so I had to make sure that I have got it right, because I have got a chance of living with this medication”. Jane [person infected with HIV];

“ when newly diagnosed, it is terribly worrying because, when you are diagnosed, you think I have X number of years to live now, what will the social life be like, what will my drug life be like when I need it. When you have been diagnosed, you need information regarding medication. Because once you win your battle over tablets that you can use, then you are ok”. Julius [person infected with HIV];

“The only area that I needed information on is the drugs. The medication, how to take it, side-effects; apart from that, the thing that I needed most in that position was moral support”. Amos [person infected with HIV];

“...so for me, the actual activity of the HIV virus in my body has been minimal, but the side-effects from my medication [ARV] has been the main area where I have needed new information. As I carry on living and surviving, you know this is an ageing population and new information is coming up about the long-term effects of the HIV virus or HIV medication, and that is a complex area really. So after becoming HIV-positive, I wanted to find more information about what was going to happen, how long I was going to live, what the medications were going to do, whether I could go ahead with the career that I wanted to do, it was huge. And for me, what was important was to find out was information directly affecting me in ways that were private”. Job [person infected with HIV].

Service providers could sometimes perceive needs not necessarily perceived by those most in need of information. One provider spoke of the vital need for information relating to testing for HIV:

“... and also the need to be tested, because people are coming to hospital presenting with late diagnosis. When the CD4 count is 0, the viral load is too high. [...] people being treated in the late stage – their life span get dramatically shortened. So, in regard to information on testing and disclosure, I think that would help a lot [...] about 55% of gay men have not been tested, they don't know their status. They are putting themselves at risk and others at risk, and AIDS can develop from four years to ten years”. Justus [information provider].

To summarise: biomedical information, including knowledge about available treatment regimens, their potential side effects, and mental health issues, as well as the availability of testing services, are crucial as far as quality of life was concerned.

5.3.5 Information on general well-being and quality of life

The findings indicated that gaining information about one's well-being constituted a major information need for most respondents. The need for information about future life prospects, including possible length of time they had to live, possibility of starting

relationships, and the effect of medication on quality of life, was strongly expressed in this study:

“People who come to us ... want to know how long they are gonna live for. That is probably the number one question. I think the key questions asked are: ‘How long am I gonna live for?’ ‘Am I going to have a relationship again?’ And those are obviously very difficult questions to answer, because life expectancy tells them that, if they look after themselves, they are going to have a pretty normal life. But you need to do it in a way that you are not promising them that they are going to live up to 93 or whatever. The other thing is about relationships. That is a difficult one because everyone deals with relationships in a very different way. Some people may decide to go out and start lasting relationships after diagnosis. For others, it may be damaging to their relationships. People ask about the medication they should be on, but because we are not trained doctors, we always say ‘you need to talk to your doctor’. But if you are not happy about anything, talk to them [doctors] about it. Maybe side-effects, change of medication. So enabling people to access the information they want. You know, if someone asks a question, we might not say this is the answer, but we may signpost them to the answer”. Jack [information provider].

Information on keeping in good health, such as maintaining a high CD4 count, and avoiding undesirable side-effects from antiretroviral therapy (ART - the combination of at least three antiretroviral (ARV) drugs - which helps to maximally suppress the HIV virus and stop the progression of the HIV disease) was needed and sought for:

“...about diets, a healthy diet, alcohol abuse, smoking, things like smoking, things that will take them down. And also people thinking because I am HIV-positive, then I am free to just date any- one, and that is even making it worse”. Monica [person infected with HIV];

“...um I needed some information about how to take that medication, and what food I should eat to help together with the medication”. Sue [person infected with HIV];

“I wanted to know how I could take care of myself. I wanted to know how to will survive with HIV. I need to know how am I going to maintain my CD4, because it was 42 but now I have 800; how can I get it up to 1000. Those are some of the things I need to know and I keep on asking my doctor and reading, you know, about how to maintain a high CD4 count”. Fiona [person infected with HIV].

In other cases, people sought information in order to know what was happening to their lives. For instance, Jane and Monica [persons infected with HIV/AIDS] reported that:

“I went to the library because I said I wanted to know more about this HIV. I have got to know what is happening in my life. ... I went to a library and I just pressed on everything to do with HIV. Just

pressed it and printed it. Press and print; I spent about £7-10 in the library, put everything into my bag. I went home and I started reading”.

“... living with being HIV-positive, and to give me confidence, I went to a pharmacist or to my GP and said: ‘I am living with HIV, I have really dry skin, what can I use?’”

“It was when I started the medication, what kind of life I was going to have or how my health would be? You know ...I have seen other people... start taking medication and the skin changes, the hair changes, you know, so that was the main focus. When I start medication, what are the side-effects of this medication? You know, will people know that this is my status? And how useful is that medication to prolonging my life? So those are the areas that I wanted to find out about; what will life be like, and how will I be”. Sam [person infected with HIV];

Furthermore, complex aspects of life, such as information about the right to choose to die, mental health issues, and ill health, prompted information seeking. For example, Job, Julius and Joel [persons infected with HIV/AIDS] respectively reported that:

“I mean there is new information coming, and the big thing for me that terrifies me absolutely is developing dementia sooner. I really don’t want to be alive suffering from Alzheimer’s disease. For me the big issue in the future will be the right to die. And being able to choose when I can die. I want to have quality of life. ... I don’t want to be kept in a vegetative state. For me in the long run, that is an issue; I want the right to choose when I can die. I don’t want to commit suicide. [...] I don’t want to get to a point where I don’t recognise myself or other people. [...] I want to be able to fight for my right to choose when I die; um you know I will make a living will. To make sure that they do not resuscitate [me]. You know, most people don’t have to make those decisions, and have these discussions in their mid-30s, but I do. And it just becomes part of your life experience. I am not dead from AIDS, but it has changed my life, my thinking totally; my life is completely different than it would otherwise have been”.

“I would like to see more information in relation to mental health and HIV. The mental side of things is important when it comes to living with HIV. Unfortunately no research has been done to investigate ways in which HIV affects the mind. I go through a rollercoaster of emotions. I am sad at one moment and happy the next. I spend nights awake. I feel lonely. I have been referred to a psychotherapist. The pressure from stress makes me withdrawn. I have friends but I don’t want to interact. There is no information on mental health”.

“It opened up a huge amount of information. It did two things: it opened up my willingness to ask questions. It is really important if you are willing to ask questions, so I opened up and asked questions; I was able to talk to people I had never met before. I was able to talk to them. It increased my willingness to get information and find ways to get information as well. And that is where I

found the confidence to ask questions about it, and the confidence to talk about it. So it was an interesting time in my life”.

5.3.6 Information about other people’s experiences of living with HIV/AIDS

The analysis of data indicated that information about people’s experiences with the condition, including living with the condition and /or being affected through illness or death of a close relative from AIDS-related illnesses, was particularly vital for the respondents. For example, Angela [person affected by HIV], Juliet [person infected with HIV] and Jack [information provider] respectively reported that:

“[...] and you know, I wanted to understand something when I was grieving; [pause]I wanted to talk to somebody who had shared my experience. You know my particular experience is unique because a child doesn’t just die in front of you. So there was nobody with whom I could share the same experience. It wasn’t about HIV or AIDS, just the experience of having your child dying in front of you, and then watch them die again four days later”;

“Listening to other people’s stories, how they got it, how they are, when they went on their meds, how it affected them, and how their life is now, you know one of the stories was unhappy but that is what helped me . . .people who have got HIV. . .Some of the stories have been helpful, you think about what they went through, they waited ten years down the road, and they come out to the other side” . ;

“I think there are two types of information about HIV. There are the raw clinical facts, the very dry information a doctor might give you. I mean the pure facts about HIV. And then there is information about HIV that you get from a positive person or someone who is living with someone who has HIV and is very close to them; I know they are both very, very valuable. But I think the people who live with HIV really do benefit from getting information from someone who is living with the condition. We get phone calls from people who would ring up and say, I have just been diagnosed. You know, I am terrified, and I am not saying ten minutes on the phone will make them calm and happy and they don’t care anymore, but ten minutes on the phone, talking to them, saying to them: ‘I have lived with this for 27 years, I am living a perfectly normal life;’ that kind of information can stop the fears that they might have otherwise. And I think that sort of information is incredibly valuable”.

The above quotations demonstrate that respondents felt that having knowledge of other people’s experiences with the condition could be reassuring and empowering. Seeking information was vital as it helped people to find information about complications they had developed as a result of being HIV-positive. The assurance that one can live a normal life

and pursue a career was an invaluable benefit derived from the respondents' information-seeking endeavours.

5.3.6.1 SUMMARY

Section 5.3 provided a rich description of the key areas about for which information was sought. These ranged from routes of transmission, biomedical information (e.g., the available treatment options) career and social reasons (e.g., the impact of HIV on pursuing a career and starting relationships), to information on general welfare and other people's experiences of living with HIV/AIDS. This section underscored the value of information in helping to maintain a good quality of life and cope with the challenges posed by HIV/AIDS.

5.4. Avoiding and ignoring information

The findings of the current study revealed that some people avoided HIV/AIDS-related information. Such avoidance behaviour was closely linked to feelings of anxiety and fear of being stigmatised. While information is often known for reducing fear and anxiety, this is not always the case with HIV/AIDS-related information. HIV/AIDS-related information, in some instances, tended to cause anxiety, fear and uncertainty. This is particularly true because to date, no other health condition results in so much stigma and anxiety as HIV/AIDS does.

Living with HIV was reported to be stressful, particularly when the media and popular discourse employed metaphors, including 'plague', 'killer disease', an 'invisible contagion', a 'moral punishment', a 'war', and an 'invader', to identify HIV/AIDS. These labels more often than not resulted in negative feelings including shame, guilt, and denial all of which lead to increased anxiety. This to a great extent explains why PI/A HIV/AIDS opted to avoid HIV/AIDS-related information.

Avoiding information occurred when people made up their minds to deliberately shut out information or not go to places where HIV/AIDS-related information could be found. Avoidance behaviour could be for a number of reasons, including avoiding becoming upset, frightened or worried as the next sections discuss.

5.4.1 Avoiding becoming upset, frightened or worried

In some cases information was avoided to safeguard against being upset, or frightened:

“I stopped accessing information from the Internet [...] because information was being made public too early in the research. A couple of pieces of research were saying one thing, and others were saying another, and I would get upset, very panicky and distressed by that. But then when I went back, there was this other research which was saying contradictory things. There is one negative aspect of gathering information from the Internet; it is too quickly and readily accessible”. Job [Person infected with HIV/AIDS];

“They gave booklets and things like that but I didn’t read them. And even now I don’t read the booklets. Because I....[pause] ah I don’t know why, I just don’t read them, because I think when you read the booklets, you start frightening yourself. Because basically you...[Silence] read about a symptom and then you think you have got it. If you’ve got an illness and you start reading about it, e.g., by the age of fifty you are going to have a heart attack, kidney failure, have this, this, this, it plants a seed of fear and then you start worrying”. Joab [person infected with HIV].

While in other cases, it was the need to avoid getting worried. For example, Joel and Jane [persons infected with HIV], respectively reported that:

“I spent many years in isolation away from people with HIV and away from people who were talking about HIV.[...] For a long time, in my isolated state, there were times when I thought, I just don’t want to know. And I think that was an effective strategy for me because I didn’t worry too much and worry is not good for HIV”.

“I didn’t want to meet anybody with HIV. And I wouldn’t come here [HIV support organisation] my social worker told me about it and I said: ‘No, I don’t want to see anybody. I don’t want to look at them. I don’t want to see what going happen to me. I am going to see people who are dying and I don’t want to see that’. Because I just thought everybody is going to look like they are dying. All sunken in, in wheelchairs, that’s all I thought. I thought I am going to see lots of people looking like those who are dying, and I don’t want to see what is coming. I don’t want to see it”.

Joy’s [information provider] observation confirms the previous respondents’ comments about information avoidance:

“...You know, when people are just diagnosed, they are so afraid and too much information too soon won’t help. Some people are so afraid and as a result they bury their heads in the sand. Sometimes they find so much information that they get so scared. Hence they need guided information, they need information with support, have things explained, and they need to see a human face”.

The above quotations vividly indicate that, although under normal circumstances, seeking information may help to reduce anxiety; seeking HIV/AIDS-related information could potentially increase anxiety and distress. Hence, people opted to avoid information in order to cope with the HIV/AIDS diagnosis.

5.4.2 Avoiding information to forget about the positive diagnosis

The data revealed that HIV/AIDS-related information was perceived to be a constant reminder that one is HIV-positive. Consequently, people avoided HIV/AIDS-related information because they did not want to remind themselves that they are HIV-positive, and only looked for information when something went wrong:

“People don’t want to know because their health is relatively good, the medication is working; well, only when something goes wrong do they ask for information. So a lot of our clients don’t need to know more information about HIV, they are not just bothered about it. They don’t want to know”.
Rita [information provider].

Ben [person infected with HIV] also reported that:

“I hate to talk about it all the time because it can be boring”.

Claire [information provider] confirmed that information about HIV was perceived as a reminder of the HIV diagnosis:

“We have clients who just come for lunch. You notice we don’t say the word HIV because that is not what they want to hear. But what they do know is that if they have something they need to know about, they can read any of those magazines. So a lot of our clients don’t need to know more information about HIV, they are not just bothered about it. They don’t want to know.... They are not proactive. They trust the doctors, and just don’t bother about information”

5.4.3 Avoiding information occurred when learning about HIV/AIDS was not deemed necessary

In other instances, people avoided and ignored information if they thought that learning about HIV was not important to them: For example, Ben and Fiona [persons infected with HIV] respectively, reported that:

“I sort of learnt about HIV/AIDS through having it. I never did intensive studies and reading about things, because it was never important to me. I didn’t get into information gathering when I had just

been diagnosed. And I see it here [HIV support group] all the time, newly diagnosed clients don't look for information".

"Sometimes when I go to [HIV support group] meetings, I just listen and it [information] goes in through one ear and out through the other because it is not important to me. Sometimes I don't think it is important to me".

The information providers expressed their frustration regarding information avoidance, particularly when people who could have benefited from available information avoided it. For example Joy and Rita [information providers] respectively reported:

"[...] the frustration is knowing that you have the information this person needs but they don't want to access it. Because there are leaflets that we put there and I know some clients could do with reading them but I can't force them to read them until they are ready to".

"The disappointment I got with providing HIV/AIDS information is when clients did not take time to read the magazines and other information resources that we provide. They only enjoy coming round to have a meal and have a chat with friends".

Such avoidance behaviour was not only prevalent among PI/A HIV/AIDS, but medical professionals too were felt to avoid and ignore information. For example, Luke [information provider] reported that when he mounts information stands in hospitals, medical practitioners avoid the HIV/AIDS information stand:

"No, they walk past. They won't ask any questions; they won't ask anything".

In this section, the researcher has attempted to illustrate that there was a tendency for PI/A HIV/AIDS to avoid HIV/AIDS- related information, most especially to reduce potential anxiety, fear and uncertainty.

5.5. Destroying information

Destroying information includes acts such as dumping, shredding or otherwise discarding information. The data revealed that this could be because of the initial conception about HIV, which generated post-test fear and anxiety and resulted in the discomfort associated with reading about HIV/AIDS:

“I don’t find it easy to read something that has the word HIV in it. No [respondent’s emphasis]. For me I will just look, pa, pa, pa [meaning quickly] then I will throw it away. I don’t find it easy”. Hope [person infected with HIV];

or perceptions that others do not want any association with HIV. This could be a known person, such as the brother of this respondent who was HIV-positive:

“My brother is a very ignorant person. He doesn’t even want to know anything about AIDS. Even if it is a booklet I have, he says that I should not keep it in the house; I should throw it away. He doesn’t want to hear, he doesn’t want to know [...]”. Fiona [person infected with HIV];

or fear of other people’ attitudes more generally, as indicated by the two respondents below:

“They don’t even want to be seen holding that kind of thing. You know when people pick up those booklets from [HIV/AIDS support centre] they will throw them in the next bin. They do not want anybody to see them holding that thing! [...] Don’t be fooled, if anybody takes a booklet out he will not take it home. He will throw it in the next bin”. Amos [person infected with HIV];

“... it is quite difficult because we have to say to clients: ‘are you ok to take this [back] home?’ If you don’t, you can just come and read it, here because some of them don’t want to take material home. You know it is a very difficult thing to do; I can’t say you must take that home and read it. For I know that if I force them to take reading material home, they would end up dumping it in the bin”. Rita [information provider].

Information overload was another reason for discarding information:

“...There is one negative aspect of gathering information from the Internet, which is that information is too quickly and readily accessible. I get my information from very reliable sources, official websites; I don't get them from random websites because there is so much information. There is a weekly email that goes out with information and, as somebody with HIV that is just too much information. So I now don't look at that information, I delete it off my email, it is information overload”. Job [person infected with HIV]

In this section, the researcher has attempted to illustrate that there was a tendency for PI/A HIV/AIDS to destroy HIV/AIDS-related information. This was particularly true when they were faced with information overload, perceptions of stigma, mental or physical threat, and even others making moral judgments about them.

5.6. Hiding information

Hiding information entailed withholding information about a person's HIV status, and concealing HIV/AIDS-related information resources. This resulted from a number of reasons as discussed in the next sections.

5.6.1 Fear of being stigmatized and judged

People may hide information through fear of being stigmatised. For example, Jane [person infected by HIV] reported that:

“I had really to work hard on issues of being stigmatised. When you tell somebody that you are HIV-positive, you are opening yourself to judgment. You judge yourself enough. You don't want others to judge you”.

Stigmatisation was also feared in the workplace:

“I would say my biggest challenge is finding work and disclosing my status to the new employer. That is one of the things I have been dreading doing. I was lucky though, ... I mean I was working when I was diagnosed [...] So I did not have to go through the process of sitting an interview and sitting down and saying: ‘Oh, by the way, I would need so many days off per year because I have hospital appointments’, and tell them why I have to go and then see their reaction: ‘Thank you very much for letting us know; we will let you know if you've got this job or not.’ And they would then come back and say: ‘I am terribly sorry, I can't employ you.’” Joab [person infected with HIV]

People also hid information because they could not accept judgement from close relatives:

“You are making a point because when my mom was diagnosed I found it hard to tell my husband because I feared the judgment he would make about my mom and me”. Loy [person affected by HIV];

“I had to decide who I was going to tell because when you tell that person, you make yourself open to judgment. And the people I want to keep by me are the people I am going to tell. I have a daughter, she is 22 and she doesn't know. She was watching Hollyoaks on the Tele, and these guys were HIV [positive] and they were kissing, and she said: ‘uh, they have got f*****g HIV’. [...] She said ‘why are they kissing’; I said ‘you shouldn't judge people’. She said ‘have you f*****g got it?’ I said ‘no’; no, see that's the point. Oh they have f*****g HIV. I said ‘oh no, no I can't tell you’. You have to choose who you tell because you can never know their reaction”. Jane [person infected with HIV];

Or even from members of the community. For instance, Julius [person infected with HIV], who feared that he would be singled out for reading an HIV/AIDS magazine in the library, shared his experience with this researcher:

“In the Library, I saw a magazine; I picked it up and started reading it. But I had this feeling that I shouldn't have picked it up because people were observing what you are reading: ‘what you are reading about?’. But if I didn't find any negativity: ‘Oh why are reading that?’ I would read it happily. So I have always got some sort of excuse because I mean, you don't need to make excuses for whatever you do; but you know, for instance, if I took a magazine to work, I wouldn't feel comfortable reading it where my colleagues are. Probably I might give it to them, so that they know, but probably they wouldn't want to know. But regarding information in public areas such as libraries or the Internet, issues regarding HIV/AIDS, then it can be kind of stigmatising there. People are identifying you as a ‘case person’ [person with questionable character], so it is a bit difficult”.

Such hiding behaviour was well known to information providers. For example, Claire [information provider] spoke of her observations relating to the hiding of information:

“....Oh that's an interesting one. For instance mothers with children, who have not told their children, they take it home but they hide it. Some people have asked us to send it to them through the post and put it in an opaque plastic bag so that no-one would see it. There was one client who said she took a booklet home and, after reading it, she hid it under her mattress; but as her daughter was tidying up her bedroom she found it under the bed, and she had hard time to explain why she was reading an HIV booklet. We have a service where we send booklets through the post but we are very careful to ask if people want this. Some people live in shared houses; some people have children who don't know. Now I know someone who hides it under the bed after reading it, and another who hides it in a specific tin”.

5.6.2 Hiding information to promote the use of HIV support services

Information providers can also themselves be hidiers of information on behalf of their clients. In some cases HIV support organisations sought to be as anonymous as possible, including putting no sign posts on their premises:

“ So I think that what we are doing here [HIV/AIDS support centre], I mean having no signs to show that we are an HIV support group, has made information more invisible because of the stigma, so it’s kind of a circle. The stigma causes someone to hide behind invisibility which causes more stigma. But hiding perpetuates stigma because we don’t tell anybody we are here, so nobody gets the information. If we had a big poster people would not come here. Even when we go out, we don’t wear a badge showing [Name of support organisation]; our building doesn’t have any signs saying ‘HIV support organisation’. When we set up information stands, our big banner doesn’t mention HIV. Joy [information provider];

or assuming a different identity when doing outreach:

“So [...] if we are doing a home visit we have to do it under an assumed identity; e.g., we are church support workers, or we are from social services. We are not from [HIV/AIDS support organisation], so when we go out of this building HIV is not mentioned”. Luke [information provider];

as well as opting to remain anonymous during HIV campaigns:

“Maybe because you don’t see HIV plastered everywhere, we don’t mention HIV on our big banner, so people come to ask us what we are all about. We at first wondered how people were going to know about us, but it has worked in our favour in a kind of way. This kind of anonymity is a way to get people who wouldn’t otherwise talk about it talking about it”. Claire [information provider]

to enable people feel comfortable with coming to the support group meetings and activities.

It is interesting to learn that, although on the surface, hiding information is a negative behaviour, it was actually useful in several ways; for instance, concealing HIV status was a safeguard against discrimination, stigma and abuse. By putting no signs on the HIV support premises, more people felt comfortable access and use the services of the support group; while eliminating big banners attracted people to the HIV stand, who otherwise would not have had anything to do with HIV.

5.7. Conclusions

In sections 5.2-5.6 the researcher has attempted to describe various patterns of information behaviour, including: seeking, sharing, hiding, destroying, and avoiding information that PI/A HIV/AIDS may adopt. Details of why and when such patterns may be adopted are discussed in Chapter eight. The current work has extended our understanding of everyday life health-related information behaviour, as opposed to most previous work described in Chapter two in subsection 2.2.1, which information seeking, particularly in academic and work-related contexts, is depicted as the predominant form of information behaviour. The researcher suggests that a deep and rich understanding of HIV/AIDS-related information behaviour could potentially inform HIV/AIDS-related information services, and product design and provision, and could result in evidence-based interventions focusing on optimally exploiting HIV/AIDS-related information behaviour, for purposes of mitigating HIV/AIDS.

CHAPTER 6- RESULTS PART 2: POST HIV/AIDS DIAGNOSIS REACTIONS

6.1. Introduction

Chapter five (the first part of the results) provided a description of the various patterns of information behaviour (seeking and sharing information, hiding, destroying, and avoiding information) that emerged from the data. Chapter six, (the second part of the results), describes post-HIV diagnosis reactions (by self and by other people over time) which might otherwise remain hidden, and/or taken granted or ignored in the design, management and dissemination of HIV/AIDS-related information.

This chapter focuses on post-HIV diagnosis reactions such as:

- Psycho-social reactions by persons infected with HIV: ‘shock and emotional rollercoaster’, ‘shame, guilt and self-stigmatisation’, ‘worthlessness’, ‘feelings of loss and grief’, loneliness and isolation, ‘fear and stress’, ‘denial’, ‘self-stigmatisation’, ‘coming to terms with HIV/AIDS’; and
- reactions by other people that endanger the status and well-being of persons infected, with or affected by, HIV: ‘perceiving persons infected with HIV as a source of contagion’, ‘making value judgments’, ‘discriminatory reactions by medical practitioners’, and ‘physical and mental abuse’.

The link between post-HIV diagnosis reactions and information behaviour will be discussed in Chapter eight, where relationships between post-diagnosis reactions and HIV/AIDS-related information behaviour are discussed in detail. The implications of post-diagnosis reactions for HIV/AIDS-related information service provision, planning, policy and practice, are discussed in Chapter nine.

6.2. Psycho-social (emotional) reactions to an HIV/AIDS diagnosis

Whereas everyone's experience was different, the majority of the respondents were overwhelmed, and experienced strong emotional reactions after receiving news of a positive diagnosis. The feelings ranged from anger, fear of people finding out, worrying about infecting others, feeling broken-hearted, hopeless, and worthless; to loss of control, worrying about dying, and what family, friends and the community would think about them. Thus, in addition to dealing with the on-going physical health problems caused by HIV/AIDS, the respondents also had to contend with constant emotional stress, including shame, guilt, embarrassment and devastation. The respondents experienced some or all of these feelings at different times during the course of living with HIV. Sections 6.2.1- 6.2.7 consist of the respondents' voices describing the psycho-social reactions.

6.2.1 Shock and emotional rollercoaster

Most respondents reported going through an episode of shock and being on an emotional rollercoaster after receiving the information that they were HIV-positive. The respondents described their post-HIV diagnosis feelings in a variety of ways. For example, Joab, Jane and Julius [persons infected with HIV] reported respectively that:

“...I felt shell-shocked, thinking how I process this information, what do I do? ... [Silence] everything! That was it”. Joab [person infected with HIV];

“When I was first diagnosed, I would have a lot of emotions in one day. One minute you could be happy, the next minute you could be sad, and it was like a rollercoaster ride. You know, you can watch something on TV which is sad and you can burst in tears”. Julius [person infected with HIV];

“...I had a phone call: ‘you need to come back to the clinic’. I said: ‘I have got cancer that is possibly what it can be’. HIV had never crossed my mind. When they told me it was HIV, I nearly died and my life just fell apart. Just fell apart. Jane [person infected with HIV].

The analysis of data revealed not only that people infected with HIV undergo post-diagnosis shock, but that members of the family of people infected with HIV also experienced extreme shock when they learned that a close family member had been diagnosed:

“I found it really difficult; I was in utter shock! ... My mom ... had a similar experience, she looked ill from such a shock. I was really shocked. You know, I was upset but I am not one who tends to be

emotional in public. I have always tried to be very strong .My grandparents didn't want me to know, but I thought my dad thought well of me by letting me know. And you know it was a real shock having to tell people, so I felt quite alone. I think possibly the most under-publicised aspect is the emotional effect [on immediate family]. I am not technically classed as a carer but the emotional strain is enormous; I have been through GCSE, A' Levels, and now a degree, having to cope with the ups and downs in my dad's experience of HIV. When I found out I had just started my GCSEs; when I was doing my A' levels, he was diagnosed with diabetes, which complicated things; and then recently, his pancreas failed". Sarah [person affected by HIV];

"I received a call from my sister and she told me that our mom had been diagnosed with HIV. I was devastated and terribly shocked. I said: 'what? my only mom!' [Interviewee shouting] I cried and cried and cried". Loy [person affected by HIV].

The news of a HIV-positive diagnosis was extremely devastating:

"When I was told that I am HIV-positive ... I cried and cried ... I cried and cried and cried ... Oh my world was torn apart". Monica [person infected with HIV];

"...he said: Oh, you have HIV'; I said: 'Oh Jesus Christ! This can't be right! This can't be right! I didn't ask for that! I haven't been sleeping around!' [Respondent cried]. I have been such a good mom, and it just blew my world apart. This year I have been in the house taking anti-depressants. You know, your world falls apart, it's the stigma; you don't know what your children will do ... are they going to be ashamed of me? ... are they experiencing the same heart wrenching....you know we have many prejudiced people. And I was prejudiced too before I was diagnosed. I knew no one with HIV, I thought it was never gonna happen to me, you know; and the devastation of it, it happened once, for a person that had not had sex for 16 years, and I got it, that broke my heart. That broke my heart". Belinda [person infected with HIV];

"...When they told me I was positive ... I said: 'Oh no, not again!' Because I lost most of my family members, my sisters, my daughter, she died when she was 19 [years]... I said: 'Oh no, I have got this thing again'. It will happen like what happened to my nephew. So I was like, Oh no! It was sad! It was sad". Hope [person infected with HIV].

Some respondents reported experiencing feelings of loss and grief:

"...at the time of receiving a positive result, it was like receiving news that your beloved one is dead. You know, when you have been well and all of a sudden you are diagnosed. " Monica [person infected with HIV];

"...you go through a period of loss and grieving. It's like a grieving process, you know, like when you have lost somebody?" Jane [person infected with HIV].

To summarise: unlike other chronic illnesses, HIV resulted in experiencing extreme stress, and emotions such as shock, sadness, anger, loss, grief, and devastation, because most people who received the diagnosis were not prepared for such news. Arguably, the severity of the diagnosis, coupled with HIV/AIDS-related prejudice, stigma and the decimating effect on your life, could account for the strong emotional reactions from most respondents. This study suggests that strong emotional reactions could impair people's cognitive ability, making it difficult for them to engage with information. The relationship between emotional distress and HIV information behaviour is discussed in detail in Chapter eight.

6.2.2 Shame, guilt and self-stigmatisation

Shame, guilt and self-stigmatisation resulting from incorrect information, conflicting ideas (e.g., what people thought about them, lack of information about HIV, fear, prejudice and discrimination), were typical post diagnosis reactions for most respondents. Most respondents reported perceiving an HIV-positive diagnosis as shameful and embarrassing:

“I mean, I didn't tell my family for the first year that I was HIV-positive because I was so ashamed and horrified that I was HIV-positive, even though it wasn't of my own making in some ways”. Job [person infected with HIV];

“...and it was very difficult for me to tell anybody, because I felt ashamed, because I should have known better, so that is stigmatising myself”. Jane [person infected with HIV].

Not only were persons infected with HIV ashamed and horrified by an HIV diagnosis, but also family members such as their children and close relatives, felt embarrassed that a member of their family had been diagnosed with HIV due to the perceived judgement from the wider community:

“My son had lots of problems with it because he had to deal with it himself. ... he was ashamed, embarrassed...” Jane [person infected with HIV];

“ When my dad was diagnosed with HIV I could not talk to my friends about it, because even though I didn't know that much about it, I knew it was bad. Because I knew it was bad, I kind of thought I don't want people starting asking questions about how he got it or start judging him and start judging us as a family”. Sarah [person affected by HIV].

In some cases people, were ashamed because they felt they had done something wrong:

“... I would like information to liberate me from walking in shame. You know it was my fault [interviewee’s emphasis]. You know it was foolish. He starts kissing me, I was leading him on, it was my fault”. Belinda [person infected with HIV].

Some of the HIV support workers also confirmed that an HIV diagnosis was perceived as shameful and embarrassing:

“...if someone came in and said ‘I have just been diagnosed’, there will be a bit of a shock, and you know that shows stigma. Well any kind of news will be a shock to somebody, but HIV seems to provoke this guilt, they don’t want to tell anybody. They are ashamed; it is shameful to be diagnosed with HIV. Then it perpetuates stigma because they don’t want to tell anybody”. Joy [information provider].

The data analysis also showed that people could feel ashamed and guilty because of contracting HIV. This discredited and tainted the way they viewed themselves and led to self-stigmatisation:

“... for people who live with HIV, there seems to be a high level of self-stigmatisation. And it becomes a defining characteristic that I am HIV-positive. This tends to become an overriding title. There is a lack of information for the general public, but also for people who are affected by HIV. Also I think that people have found it difficult to keep away from stereotyping and stigma. ... The fact is that there is not enough information about HIV, so when you are diagnosed, you just perceive the risks and taboo surrounding HIV, and you stigmatise yourself. It kind of goes around in a vicious circle and people stigmatise you, all because of lack of information. ” Claire [information provider];

“...it is very hard to kind of explain. Um because of stigma and discrimination, and self-hatred and low self-esteem. There were a lot of negative ideas I had about myself any way, and as I grew up there were lots of negative ideas in people’s minds associated with being HIV- positive. So you have to kind of come to terms with those things”. Job [person infected with HIV];

“...Because I was scared. Nobody knew it was all in my head. I was losing weight because of worrying, and when you lose weight, straight away people say: ‘Oh, has she got HIV?’ You know they just say it. I was all sunken in, my legs lost all their weight, my boobies were gone, everything just gone, and I was depressed, and if I went outside everybody could see. And that is why you stigmatise yourself. I had to work really hard on the issues of being stigmatised”. Jane [person infected with HIV];

To summarise: shame, guilt and self-stigmatisation could impute inferiority to persons infected with HIV/AIDS, make them feel less confident and anxious about themselves and consequently interfere with their well-being. These feelings could influence interaction with HIV/AIDS-related information as will be discussed in detail in Chapter eight.

6.2.3 Worthlessness

One of the reactions to an HIV diagnosis was feeling worthless. Anticipated and experienced reactions from other people accounted for feeling worthless and hopeless:

“You feel like you are on a scrap-heap, useless and rubbish, and it’s not good when you feel like that. We all have sexual needs, and I feel I have to put my sexual life on hold because you don’t feel great about yourself, you feel you may put the other person at risk, you just don’t feel whole anymore; it’s like something has been ripped out of you. You feel that you have been damaged and you have got too much baggage, you don’t want to meet new people either, you feel judged. I go through a rollercoaster of emotions. I am sad at one time and happy the next. I spend nights awake. I feel lonely. I have been referred to a psychotherapist. The pressure from stress makes me withdrawn. I have friends, but I don’t want to interact”. Julius [person infected with HIV];

“..You know, when you are diagnosed, you think you gonna have no life, you gonna be by yourself, one is gonna want you, you are not worthy, you think all these things. You see you are finished now. No man will love you anymore; you can’t get love, nobody, and nothing. You think that is what life is gonna be like, you will be by yourself for ever, like you have got leprosy. That is what I thought to myself”. Jane [person infected with HIV].

Feeling worthless, coupled with fear, shame and guilt in some cases accounted for negative behaviour such as excessive drinking and drug misuse:

“.... my friend’s boyfriend told her that he had slept with someone who is HIV positive, and my friend needs to go for a test so she was very panicky, very devastated; they were drinking for three days, smoking weed, getting drunk, just locked herself in, waiting for death”. Andrea [person infected with HIV].

While HIV/AIDS-related distress in some cases resulted in self-destructive acts such as being suicidal:

“...you’re put in that kind of situation, you have got a number of options: one of them is to go to pieces and lose it, and I nearly did and I wanted to kill myself, but people around me convinced me not to, and I didn’t”. Job [person infected with HIV].

In summary: descriptions of the forms of worthlessness experienced illustrate that HIV could compromise people's well-being and quality of life, and deprive people of the opportunity to engage in normal social activities. Loss of self-worth could lead to emotional distress, generate feelings of inferiority and lead to isolation. Worthlessness could also result in vulnerability and stop people from doing things they could normally do for themselves.

6.2.4 Feelings of loss of control

The respondents reported experiencing loss of control which took various forms. In some cases, it was in the form of an inner voice that constantly reminded them that they were HIV-positive.

“You know, living with HIV is like living with someone who wants to control your life. And then you have to keep fighting. Like somebody is at your back, you need to keep doing like this [respondent showed a gesture of pushing something away]. Like you walk in town, you see somebody who fancies you, and they really like you and they come and talk to you nicely; then suddenly that person [inside you] comes and says ‘ I am here, you’ve got HIV’ [interviewee’s emphasis]. It is so it is frustrating. There are simple things you can do yourself, but you don’t feel like doing them. ... you just feel as though there is somebody behind you telling you ‘don’t do it’”. Monica [person infected with HIV];

“...I can’t think. Every time I try to think I feel someone [ghost] at my back saying ‘don’t bother anymore’. I am psychic, so when I talk to myself they answer me back so they get on my nerves. It’s like when you want to go out and meet people, you end up having second thoughts: ‘No stay here’ [interviewee’s emphasis]. If you go drinking you still have those background noises in your head that you have got this thing which is going to be affecting your life all of the time”. Julius [person infected with HIV].

In other cases, the experience of living with HIV was like being burdened with a heavy weight:

“...Well, you know what, I felt as though I had to get it off my chest [emphasis]. Even though I had told one person because I thought this is too much for me to hold in myself, I had to PPUUU [put it off the chest]. That was the first time I told somebody that I have got HIV. I had taken a big weight off my shoulders”. Joab [person infected with HIV].

“It can have very heavy mental effects. It feels like you have got a ton weight on your shoulders, which you don’t like”. Belinda [person infected with HIV].

To summarise: loss of control, particularly in the mind, could compromise the individual's ability to live an independent life, result in isolation. Similarly, feelings of carrying a heavy weight could be emotionally destructive especially if the HIV status needs to be concealed to avoid social stigma and discrimination.

6.2.5 Fear and Stress

The respondents reported that they experienced acute fears of the unknown, of other people's reactions, of physical loss and painful death, which resulted in stress and worry. The data revealed that the respondents constantly had to deal with stress. They were not only worried about death and dying, but also about the medication, including how long the medication would be effective for, and its side-effects:

“When newly diagnosed, it is terribly worrying because, when you are diagnosed, you think I have X number of years to live now, what will my social life be like... Even when the pills worked, we didn't know how long they gonna work for. And then we started hearing of people dying from heart failure, kidney or liver failure, because of the drugs. So I assumed they were just giving me a few more years. So I have been living the last twenty years as if each year is my last year. When I got sick three weeks ago, I started worrying because they say that people with a late diagnosis who start treatment late can expect to live at least 20 years. I have already had 21 years”. Ben [person infected with HIV].

The respondents were particularly worried about disclosing their status to their children:

“I found that really, really hard. I was really nervous about the whole thing. So I was really, really worried about all these things and I had to tell my kids. I was worried ...I couldn't ask anybody because I did not want to broadcast that I have HIV. Jane [person infected with HIV].

They also lived in fear of other people finding out about their HIV status:

“...Well, I didn't disclose it to my children for 12 months. ...I lived in fear of them finding out”. Jo [person infected with HIV];

and fear of other people's reactions, such as blaming and judging, which resulted in isolation:

“...I spent many years [20] in isolation away from people with HIV, and away from people who were talking about HIV. The isolation was mainly self-imposed, because when I was first diagnosed HIV was a taboo subject. Nobody wanted to talk about it”. Joel [person infected with HIV];

“...You know, sometimes if people know, maybe you have a friend who knows you are HIV- positive she/ he will tell others. And you just feel, ooh those people know that I am like this, and you just want to do things on your own. You don’t want to mix with people. Yeah, I don’t like mixing because I don’t know what people will say about me. I don’t like talking about private things. When you are like this [HIV-positive] you are stressed. It’s like you feel isolated, you know what I mean? You just feel like the world doesn’t like you, even God doesn’t want you, why is this happening to me?” Hope [person infected with HIV];

“You lock yourself in the house, and you treat yourself as worthless, you don’t want to see people, you don’t want them to look at you, you do not want to see anybody, you lock yourself away, you don’t want to go out, and you don’t want to take on their judgments of you, because you judge yourself enough; that’s where isolating yourself comes in”. Jane [person infected with HIV];

“... sometimes they [my children] come home and they say: ‘Where had you been, we came on Friday, and you didn’t answer the door’; and I say: ‘Oh I went to a counseling course’. But I wasn’t, I was in the bedroom and I didn’t answer the door because they would see that I had been crying”. Belinda [person infected with HIV].

One HIV information provider also confirmed that PI/A HIV/AIDS live in fear of other people’s reactions and judgments of them:

“Here [England] people live in isolation, with the fear of people finding out, and they are not ready to say this is who I am, it just happened to me. Because a lot of people feel they have done something wrong. And we tell them it is a virus; you don’t apologise [interviewee’s emphasis] for catching a virus. You had sex; everybody has sex, so why apologise?” Justus [information provider].

HIV support workers responded to their clients’ fears by not interacting with them outside of the HIV support group premises:

“...that’s complicated, so much so that if you meet any member of the support group in town, we don’t talk to you. We don’t know if you want that interaction or not. For some people, when they are out of [name of support group], they don’t want to be associated with [name of support group]”. Rita [information provider].

To summarise: HIV/AIDS-related fear, stress and anxiety, can potentially undermine building social networks and relationships, which can also result in PI/A HIV/AIDS leading isolated, unhappy and depressing lives. This could influence HIV/AIDS-related information behaviour in various ways. Chapter eight discusses the relationship between stress and HIV/AIDS-related information behaviour.

6.2.6 Denial

The study identified two main forms of denial; namely, denying one's status to other people, and self-denial. Both forms of denial entailed refusing to acknowledge the unacceptable truth that one is HIV-positive.

Self-denial entailed denying one's HIV-positive status:

“...After diagnosis they were trying to emphasise certain things to me but I wasn't taking any notice. NO I AM NOT, I AM NOT. They were trying to emphasise to me that it was a serious disease, and I am like 'I don't think so, I don't think so'”. Juliet [person infected with HIV];

“...That is when my doctor came in ... and told me that I am sorry to tell you that you are suffering from HIV. I said, 'WHAT?' [Interviewee's emphasis] 'That you are HIV-positive.' You know! that didn't really click with me I didn't really pay much attention that she is telling me that I am HIV-positive. Why would she tell me that I am HIV-positive? [Interviewee's emphasis]. I mean, I didn't know that I was”. Fiona [person infected with HIV];

I was in a state of denial more than anything else. That didn't happen. This didn't happen. So every time I got a cold I thought I am dying now; every time I did not feel well I thought I was gonna die now”. Ben [person infected with HIV];

“On 13th May, 2004 I went to the hospital for testing. They told me they have found something in my blood and it could be HIV. I was in denial...” Julius [person infected with HIV].

In other instances, denial entailed making excuses and being untruthful in an attempt to conceal the HIV status from family friends and/or the wider community:

“.... in this year there has been so much, so much deceit. When I come here [HIV support group], because they know I don't go anywhere so [Name of support worker] said, just say you are a counselor. So I am on a counseling course. My son says 'Oh you started a counseling course, oh we are proud of you mom'”. Belinda [person infected with HIV];

“When I come here [HIV support group] I tell them that I have a job where I work as a volunteerespecially at first you walk around thinking, who knows? Who doesn't know? Because you are so traumatised by yourself without realising that you're traumatised, you are passing those vibes over to other people. Because you look stressed, and when they ask you why you are stressed, you can't tell them. Then you start making excuses. You find yourself telling little white lies as to why you are stressed and why you look like that. You are looking for excuses for yourself” Jo [person infected with HIV];

“...I mean I have side-effects in the form of sleepless nights, weird dreams, and every so often I get a bit of a head full of cotton wool and I feel a bit woozy; I get dizzy spells due to the side-effects of the medication. So when people ask you how are you feeling, you think, oh I am a bit woozy, but you can't say: 'Because I am on these tablets, I had a bad dream last night.' So I tell a different story from the real one. So you live the life of a lie” Joab [person infected with HIV].

Denial, particularly refusing to acknowledge and hiding the HIV status, appeared in some cases, to be responsible for late HIV diagnosis:

“....my husband was down I said to him: 'no you need to go for a check-up' and he used to hide. He used to refuse; I think he did it [tested] himself but he didn't want to tell me. But for me I knew that something was wrong somewhere you had better go for a check-up and he didn't even go. So this other time I said: 'You know, I will do it myself because, if you are hiding something if you are not telling me, I will go myself for a check-up. But if I find out that I am like that, [HIV-positive] I will sue you'. And he said alright, he was like no, no, no, he didn't want to say it. He was already like that [HIV-positive] but didn't want to say it. We went together and I asked the doctor can you do all the check-ups? And he said 'no I don't want it', and the doctor [said] 'since you don't want it, that is it'”. Hope [person infected with HIV];

“You know there is a time she phoned him [GP] and I said: 'Tell the GP what is happening'. There was a point in her conversation where she went, yeah! That kind of 'yes', which implies there is somebody else in the room here; I can't say anything else. So when I thought about that later [after she had died] I thought yeah there is something they knew between them. I could just tell by this 'no'. And so there I am thinking, you have been lying to everyone for a year, and lying to yourself as well. I had been told that she was HIV-positive it was the first time I saw that she knew. Yes, she had known for over a year. She had gone to see a gynecologist and that gynecologist had said to her: 'You are certainly HIV-positive. You need to go for a test. Promise me you will'. And she said she would, but she didn't. Initially she would have been lying to herself, trying to deny that she wasn't”. Angela [person affected by HIV];

“The doctors asked us to test my daughter, I think it was ignorance ... I couldn’t accept that thing [HIV] was happening in my house. I wouldn’t accept it. When they said she needed an HIV test I said no. I said no she is only 17 so doesn’t need to know all these things. The day before she died they tested her; they found out that she was HIV-positive. But she couldn’t survive, she died the following morning. So since then I regretted saying no; that was wrong. That was a wrong decision”
Martha [person affected by HIV].

To summarise: the experiences cited suggest that denial is a form of avoidance employed to diminish perceived risk and to deal with the emotional aspects of living with HIV. However, it could be detrimental; particularly if it prevents people from seeking medical support and information they need to make informed choices and decisions.

6.2.7 Coming to terms with HIV

The data also revealed that respondents eventually came to terms with their HIV status. For some people it had taken as long as 25 years, others spent five years or less to come to terms with the illness, depending on the circumstances they experienced during the course of the illness. One of the reasons given for coming to terms with HIV was accessing information about routes of transmission of HIV and HIV legislation:

“This place [Name of HIV support group] is brilliant. It has helped me so much. I got access to basic things [information] like; I almost hit my daughter because she used my toothbrush. I thought I had passed it on to her. I was thinking all the time I could pass it on to her that way. So I had to stop all these things”. Jane [person infected with HIV];

“...When I was first diagnosed I didn’t tell anybody, but as I have grown more confident, and particularly since the change of the law in this country, and since I have been protected by the law, by the Disability and Discrimination Act (DDA), knowing that I am covered by that, that is really a significant shift and change for me to be more open and honest at my work-place. Now the fact that I know, I am in a situation where I can talk openly about my HIV status. It is because of the process I have gone through, combating the stigma and discrimination that is inherent with this. Those kinds of things were what enabled me to get to a point where I am completely open at work; I am also completely open with everybody in my family. Everybody knows, I am not ashamed any more of having an illness, and I have talked to young people for the last four years and I will continue to do that for the rest of my life”. Job [person infected with HIV].

Meeting other people infected with, or affected by, HIV also facilitated coming to terms with HIV:

“...when I started coming to [Name of HIV support group] I met people that I used to meet in town. They were also coming to [Name of support group] to get support. Because they were looking so healthy when we met at [Name of support group] I knew we were in the same boat. That also gave me the hope and confidence that people can have nice bodies, people can be beautiful and handsome even when they are HIV-positive”. Sam [person infected with HIV];

The respondents also came to terms with their status when they stopped worrying about other people’s reactions to, and judgments of, them. A typical illustration of this is provided by Jo and Amos [persons infected with HIV] who reported, respectively, that:

“...Once you decide I don’t give a damn what they think any more, but it still sometimes comes back. Stop it, I am not hurting you, I am not having sex with you, you come to my house, you see I do everything right, I don’t touch food unless I have rubber gloves on, I sterilise my side-stands, everything everyday just in case; you know what I mean, I do everything by the book. To me, to my standard, and if this is not good enough for you, don’t come! That is the attitude that has come eventually”.

“...I say no retreat, no surrender, the struggle continues. Fighting stigma is very simple. I don’t care who knows that I am HIV-positive, I don’t give a f***, I don’t care, let them talk about me I am not worried. Simple. I always ask people who are talking about me: ‘have you been for the test? Do you know your status? Show me your medical certificate if you are ok!’”.

In other instances, persons infected with HIV made a personal choice to move on with normal life regardless of their condition. For example, Jo [person infected with HIV] reported that:

“I just said: ‘Stop feeling sorry for yourself [Interviewee’s emphasis]. You got yourself into this mess and you are going to get yourself out [High tone]. And you are gonna prove to this world that you are gonna live as long as anybody else’. But that was me, that was my personal choice, and I tried to instill it into other people who are suffering. It took 18 months for me to make a personal choice to develop a fighting spirit. But it was only after trauma that it came to me. Had that trauma not happened, I would have been struggling along and going down. Something traumatic had to happen for me to turn the tables around. I don’t give a damn who knows now. They have messed with me long enough. I think we’ve got to instill that fighting spirit into people. It isn’t end of world for you. So don’t lie down and take it”. Jo [person infected with HIV].

Job [person infected with HIV] who had lost hope after he was diagnosed and led an irresponsible financial life style which dragged him into executive debt, also reported about his new prospects:

“...I plan to be a play therapist. So I have a very full life and I have a future, and I didn’t have those things when I first became HIV-positive. And the other thing that I am trying to do because of those two – three years when I thought I was gonna die now, I was irresponsible with my money so I have got myself into lots of debt. So I have been paying it off. I paid off £16,000 in the last two years, and I have got another £16,000 to pay off, while still paying my bills and having a life to live now”.

The data suggests that coming to terms with HIV is vital in the fight against HIV because it could transform people who are ashamed and embarrassed about HIV into agents of change. For instance in the current study some people who were indifferent about HIV became involved in school outreach programmes, conducted HIV-awareness sessions, or even participated in radio and TV interviews to create awareness about HIV. The extracts from Ben and Joel [persons infected with HIV] illustrate this:

“Yeah it takes a while to come to that point. It’s easier for me to talk about it now and say it is nothing, but for years it was something. You know I have got to this point after 20 years. In 1991 and 1992 I wouldn’t talk about it. It was in 2008 that I came to England, I had lived with it for 19 years so I had come to terms with it”.

“.....I would personally read HIV/AIDS information anywhere, I have sat on trains and read HIV literature, such as Positive Nation and Treatment Updates, so it is not something that worries me. I know lots of people who would be extremely unhappy to do that. It is way along the process of people accepting the condition. You know, I am 25 years old [of living with HIV], so it’s not a big thing to me. [Was it a big thing to you? (Interviewer)] Oh yes. I mean for many, many years I wouldn’t even say the word HIV; it was something I didn’t want to talk about at all. Now, I can talk about it in public, it is a very big change over time”.

Although the data revealed that it was beneficial to come to terms with HIV, some people found it extremely difficult to do this:

“I have really slowed down. I have not come to terms with it. It is doing my head in; I don’t know what to do”. Juliet [person infected with HIV];

“I am doomed then, because I have got diabetes, so it’s gonna attack that; I have got a bad heart, so it’s gonna attack that; I have got arthritis, so I am doomed; I am just waiting now for it to start

attacking [participant cries again]. I don't know if it will attack my heart, I don't know if it is gonna go for my back, ankle. So I live in fear of that". Belinda [Person infected with HIV].

The above discussion illustrates that HIV is unique because of the nature of transmission, the poor prognosis for those infected, and the length of time one can live with the infection. The extreme emotions experienced make coming to terms with HIV difficult. This explains why people may require as long as 25 years in order to come to terms with HIV, while others just live with the disease without necessarily coming to terms with it. This knowledge is vital for improved HIV information service provision.

6.2.8 Summary

Sub-sections 6.2.1- 6.2.7 have provided insights into the psycho-social experiences and perceptions of PI/A HIV/AIDS, including what it is like to face a diagnosis with its prospect of a life of potential uncertainty, living with a condition for which there is currently no known cure, and for which such conventional palliative treatments as do exist may have unpleasant and toxic side-effects. The experience of people who have discovered that they, or their loved ones, have HIV is traumatic, devastating, frightening, confusing and depressing.

The study suggests that emotional responses like denial, a form of avoidance (Lazarus, 1993; Alonzo and Reynolds, 1995; Case et al., 2005), and coming to terms with the HIV status were employed to diminish the perceived risk and to deal with the emotional aspects of living with HIV (as discussed in detail in Chapter eight). From the post-HIV diagnosis reactions described by respondents, it can be inferred that an HIV diagnosis can potentially lead to psychological damage, greatly compromise self-esteem and can lead to behaviours such as the misuse of drugs and alcohol, which could potentially increase the risk of HIV/AIDS transmission. Given the extreme trauma and feelings of devastation, the finding that the information behaviour of the respondents was influenced by emotional as well as logical drivers (as discussed in Chapter eight) is hardly surprising.

6.3. Other people's reactions to HIV/AIDS: prejudice, stigma and discrimination

Although effective long-term treatments have reduced the visibility of HIV infection and have enabled more people with HIV to lead normal lives including staying in work, the

current study has revealed that prejudice, discrimination and stigma remain a reality for PI/A HIV/AIDS. Stigma has a number of repercussions, the major one being its potential to divide humanity into ‘them’ and ‘us’. Stigma not only has a substantial impact on people’s physical and mental health, but it can also block HIV/AIDS-related information dissemination, and undermine efforts to prevent and manage the virus. Sub-sections 6.3.1-6.3.4 describe a range of apparently arbitrary negative reactions, such as cruelty, intolerance, dislike and moral blame, which PI/A HIV/AIDS experienced from other people. Typical perceptions of HIV by other people included viewing PI/A HIV/AIDS as alien, anti-social, dangerous and deviant ‘others’. Respondents reported reactions such as: considering persons infected with HIV as sources of contagion; making value judgements; discrimination, gossip, breaking confidentiality; and physical and mental abuse. A detailed description of people’s reactions to HIV, as reported by the respondents, is given below.

6.3.1 Perceiving persons infected with HIV to be a source of contagion

One major reaction to HIV by other people was considering persons infected with HIV to be a dangerous source of contagion. People feared sharing houses, toilet seats and cutlery with persons infected with HIV, because they thought they would put themselves at risk of contracting HIV. For example Jane [person infected with HIV], whose son reacted to the news of her diagnosis by taking his children away from his mother, and by not talking to her for fear of putting himself and his children at risk of catching HIV from her, reported that:

“My son, when I told him, he said: ‘God!! Mom!! My f****ng kids! Are they safe?’ Those were the first words from his mouth. ‘What is all this f****ng HIV you are talking about? ... F****ng hell mom! are my kids safe? You had my kidsoh my God!’ And he said many nasty things. He took away his kids, he stopped talking to me”. Jane [person infected with HIV].

Similarly, Martha [person affected by HIV] considered her daughter dangerous and was not helpful at the time she needed her most:

“It was like, you know, it was a week before she died that we knew she was positive. Oh during that week there were a lot of things [negative reactions] going on. Because like the cups, when she was coughing we said oh no, you can’t use her cups, you know what I mean? It was too much I don’t even want to talk about it. I feel sorry for her that she was treated like that. And I remember I took her to the hospital toilet and she was vomiting, she said mom! I am vomiting come in! I couldn’t bear it, so I

didn't help. I feel sorry because I was so ignorant about HIV. I didn't have more information about this thing. You know the problem with HIV, we only know more about it when we get it".

The data revealed that people were terrified that they could contract HIV by associating with people infected with HIV. For example, Peter [person affected by HIV] reported that:

"...like me, I still that fear that I am at risk. I know about the disease but on a personal level it is different. I have had people [family members] with HIV but I still have that fear. It can never be guaranteed that I am safe on this thing. Trust me, if my housemate told me he had HIV I would fear to share a toilet seat with him. I will be like I am not gonna sit on that toilet. I am being frank with you, I would not use the toilet seat. I know HIV is got from intercourse and sharing blood, but I still have that fear, I am not gonna sit on that toilet seat. I am not gonna share my towel with you, I won't use my cup with you. It's kind of like oh no he has HIV, I don't know what may happen. It is a terrifying disease. ...I don't know, it is a disease we don't understand. It's a disease we don't know everything about. I still can't feel safe. You can easily get it. That is how I see it. HIV/AIDS, it's a long story!"

I had seen people's attitudes towards my sister. When she would go visiting they were like 'has *****[name withheld] been here? Did you wipe your chairs?' I said 'don't be f*****ng cheeky'".
Jane [person infected with HIV];

"They do not know about it. Just they think -a dirty disease! [Interviewee's emphasis]. I used to get to pubs, I used to go, and when people started avoiding me, I told them that the only 'AIDS' I have got are my hearing aids. Because everybody went: oh don't touch her, she has got AIDS. Oh, people were so ignorant...you are like an evil person. Don't ask me, I can't explain it! [Interviewee's emphasis]. It is horrible; everybody thought I was the Grim Reaper. Everybody went 'Oh don't touch her, she has got AIDS'. I was completely screwed up because everybody was tyrannical".
Juliet [person infected with HIV].

The data indicated that some countries denied entry to persons infected with HIV, because they were terrified that allowing them entry would pose a health risk:

"Having somebody turn me away because they have seen my medication! If you were travelling somewhere, you would not be stopped because of having cancer. There are many countries in the world where you are prevented from travelling into those countries if you have HIV medication. There are 15 countries where you would be treated like a murderer and criminal. You know, shackled, hands together, legs together, stripped of your own clothes, put in orange overalls, frog-matched out of the airport and then to a psychiatric isolation ward and then made to stay in bed until they could deport you, and then stamp HIV all over your passport Job [person infected with HIV];

“In my county if you test HIV positive you are confined in hospital where you live the rest of your life. It is horrible”.Hajara [person affected with HIV].

The above discussion has shown that people diagnosed with HIV often become victims of discrimination and abuse because they are perceived to be social deviants and a dangerous public health threat. This could result in social rejection which could be extremely discrediting and emotionally disturbing. Details of the effect of negative perceptions about HIV, and PI/A HIV/AIDS information behaviour are discussed in Chapter eight.

6.3.2 Making value judgments

Other people’s reactions to HIV also involved making value judgements about PI/A HIV/AIDS. The findings indicated that making moral judgments about HIV was deeply rooted in British culture where talking about sex is taboo:

“Well, this thing is so bound up with sex, and sex is always bound up with moral judgments. And it’s that combination. Certainly in Britain, talking about sex is something that we don’t necessarily do very easily. I mean the British culture is particularly renowned for it. And there are moral and religious judgments and beliefs which affect how people view people having sex. And then there is the other issue that, if you associate HIV with homosexuality and you don’t approve of homosexuality, it just adds to the negative view you have about the whole thing. It doesn’t matter whether it is right or wrong, it’s all those value judgments that then affect the context in which you think about HIV/ AIDS”. Angela [person affected by HIV].

Thus people who contracted HIV were considered immoral:

“When you tell them that you have HIV... they will not take you to be a good person, because to get it you must have been going with a lot of men. May be you are a prostitute”. Fiona [person infected with HIV];

“....it is the stigma which goes with the disease. You know, to be HIV-positive doesn’t mean that you are a loose person, with no morals”. Amos [person infected with HIV].

In extreme cases, other people wished that persons infected with HIV would be exterminated:

“... I talked about a university lecturer who said I should be put on an island and be shot if I tried to escape because I was automatically gonna be passing on HIV. To me, that is deeply wrong and it was terrifying for me to think that he was an educated university professor who was saying the most

ignorant and unspeakable things you could imagine in front of my face”. Job [person infected with HIV].

Making value judgements also entailed withholding basic human rights like acquiring a mortgage and /or an insurance policy:

“I own a house but I lied when I applied for my mortgage, because at the time, if you said you had HIV, they couldn’t give you a mortgage regardless of the HIV result. I mean, how ridiculous is that, how irresponsible is that, and how dangerous is that. How cruel? I mean [name of person affected by HIV] who lost her daughter, had got a mortgage, and initially the insurance companies refused to pay out on the policy. How is that acceptable? Why are moral judgments made that someone who dies of cancer can get a mortgage paid off, while someone who gets HIV and dies can’t? For me that is wrong, it’s discriminatory and it produces stigma”. Job [person infected with HIV];

showing no compassion towards persons infected with HIV:

“..When my sister was diagnosed with HIV, I said she must have known! I don’t give a f*****g damn! She said she didn’t know; I said bullsh*t, you must have known! I didn’t understand it at all until I was diagnosed myself. When I didn’t know that I had it. It was wrong! You do not ever know until you get tested”. Jane [person infected with HIV];

“...because some of the service providers started judging me because I was HIV-positive and said that I stink. [...] Oh he has got HIV, he is going to get AIDS, not sympathetic at all. And it is really bad for health workers to behave like that”. Julius [person infected with HIV];

and accusing the person of being reckless:

“When I was initially told the cause of death of **** [daughter’s name], my reaction was judgmental, my instant reaction was to be angry; although I didn’t shout, inside I was angry and blamed her for sleeping around. I would rather put it this way: **** [Daughter] was always a racing driver and she died as a racing driver”. Angela [person affected by HIV].

In the light of the views expressed by respondents regarding making moral judgements, one can infer that ascribing moral blame to people who are diagnosed with HIV, or those who have special relations with them, could jeopardise compassionate care for them. Guilt resulting from value judgments could undermine people's self-esteem and ultimately hinder active engagement with information for problem solving purposes, as will be discussed in Chapter eight.

6.3.3 Discrimination in medical services

The respondents complained about widespread and/or persistent hostility, stigmatising and discriminatory attitudes among various categories of health professionals. Although medical practitioners were expected to apply universal health and safety precautions irrespective of whether one is HIV-positive or not, some medical professionals behaved in an emotional and reactionary manner when it came to dealing with persons infected with HIV. Behaviours ranged from booking persons infected with HIV at the end of the clinic or theatre list, and /or putting them in isolation rooms; to breaking confidentiality, denying them treatment, and wearing two pairs of gloves to administer treatment. The persons infected with HIV/AIDS interviewed had experienced at least one, and sometimes several, forms of negative behaviour during hospital visits.

Some people were booked at the end of clinic or theatre list, had a big sticker [HIV] posted on their files, or experienced a doctor wearing two sets of gloves before treatment was administered, because the medical practitioners were so frightened of potential infection:

“I had a trigger finger. These two fingers were locking. I had to go to the [Name of hospital] and I had to go to the day surgery clinic. Then I had to have injections. I was there from 12:30, and they were seeing different people at different times, but I ended up being seen at 4 o'clock. I was put at the end of the clinic. I didn't say anything at the time, but the doctor put on two sets of gloves just to give me an injection. Six months later it happened again, and they [fingers] still lock. So I see a new doctor, a surgeon; she says we will operate, it will be better for you; I said fine. I have to go at 12:30; I get called through to get pre-op assessment, and I asked what time I am going to be seen;, she says you are at the end of the theatre list. I asked why? She said it was due to the risk of infection from me. And I said: 'I am more at risk of infection from somebody else; because you know my status that I am positive. So you should take precautions'. They could have operated on somebody else who they do not know is positive if the person hasn't told them; maybe that person themselves does not know and they can pass the virus on. But they told me I was positive and I was going to be the last".
Joab [person infected with HIV];

“...like this other time when I went to hospital, somebody had to put on two sets of gloves. ...I was having this implant, so the nurse had to put on two sets of gloves ... she was shivering [panicking] and I had a big bruise. When you have got this [HIV] they treat you as if you are useless”. Hope [person infected with HIV].

Belinda [person infected with HIV] who was also booked at the end of the theatre list, and had a big red sticker [HIV] posted on her file, began her narrative by commenting:

“...I went to hospital last month [May 2010] because I needed injections in my back and I had to tell them I was HIV-positive and that was hard. And it was also sad because they left me to be the last patient to be seen. I went in at 1:00pm and didn't get out until 7:45pm in the evening. I was the last patient. It was hard because I didn't want to tell my two sons. They said if they gave me a sedative, I needed to have someone to take me home. I said I didn't have anyone and they didn't give me a sedative, and that is why I passed out. I said I didn't have anyone because I didn't want my children to see that sticker on my file. I got a taxi went home; my son asked, 'what happened and how come you took so long?'”

Jane [person infected with HIV] also complained about being booked at the end of the theatre list when everything was going to be cleaned anyway:

“When I went, they said to me: 'We have put you to the end of the list because of your state'. And I was crying and being sick and all sorts of things. They put me last in the queue for my own health because they do not want to pass infection on to me. They shouldn't do that because everything should be clean anyway; exactly, so it doesn't matter if I went third, first, second or last. Everything should be clean anyway. But that's the thing that they do, which is not good”.

The findings revealed that persons infected with HIV were treated differently as soon as it was discovered that they were positive. In some cases, people were moved into isolation rooms:

“I was admitted into a separate room so as not to mix with other people. I was initially admitted with other people, but when my results came and I was positive, I was transferred because of my HIV. They moved me to a room of my own”. Fiona [person infected with HIV];

“... I had a friend who was admitted in [other city]; she is HIV-positive. They had to put her into a separate room; you know nurses had to wear three pairs or double gloves. So she thought, because I have got HIV/AIDS, I am discriminated against. I am of no value to them”. Sam [person infected with HIV].

In other instances, discrimination in medical services involved discontinuing or changing essential medical services. For example, Belinda [person infected with HIV] reported that:

“I went to the hospital the other day to get the injections for my back pain and they said they can’t give me the injection [respondent cries], so that was it. They basically shut the doors and said goodbye”. Belinda [person infected with HIV].

Jane [person infected with HIV] was treated differently after a doctor disclosed her status to her GP.

“...my brain was just exploding, I did not know where to turn, and what to do or anything. When I knew doctors are gonna touch me like that, I had to tell them first, and I found that really, really hard. So I had to go to the clinic I was attending at the time, and asked them to phone that doctor specifically and tell him how bad I feel. I was really nervous about the whole thing and that doctor went on and told my GP when I asked him not to. And I am taking him to court for that, because it is a breach of confidentiality. When I went to the hospital and told my doctor that I was HIV-positive, in between this my thyroid went high, so I was changing the amounts I take. And very often, I would make an appointment with the nurse, I did not have to see the doctor, she would take my blood and then let me go. That is all I had to do. And I had been doing that for a year with this doctor. Then, all of a sudden I got a phone call. I made an appointment with the nurse, for the blood test as normal; I phoned the clinic and said: ‘Do I have to tell the nurse?’ They said: ‘No you don’t’. When I went in the nurse said: ‘You have got to see the doctor’; I asked why? She said that the doctor will offer you the blood test. I said that is unusual! I had no clue that they already knew that I was HIV-positive. And I said that is unusual, so when I went to see the doctor, I sat on the chair and the doctor said to me: ‘So, you are an HIV patient?’ I said ‘What?’ So now the doctor has to do the blood test and the nurse can’t do it because I am HIV-positive? So they treated me differently as soon as they knew I was HIV-positive. I had that test every three months before I was diagnosed with HIV, so why was I treated differently. That did happen. It did happen, and that was wrong. That was a nasty experience. And that really, really, really, really upset me and I never went to see a doctor for three months, four months. I refused. They had to have a meeting with all the doctors because I said no, never again, because he shouldn’t have done that because that was wrong. Everybody tells me that it was wrong. And you know, when you are already HIV-positive, you do not need to be treated like that, especially by doctors. It’s wrong, wrong, wrong”.

In other cases, medical practitioners were perceived to behave badly when they discovered from the patients’ records that the patient before them was HIV-positive:

“I had experience of stigma and discrimination from a dentist. And I still don’t have a dentist today. This is 10 years ago. I went to have a check-up; I was brought up to have a check-up every six months. I had to explain to them that I was HIV-positive because they were going to do work that

could make my gums bleed. And they are using implements where they could injure themselves when there is blood in your mouth. It is called universal precautions, you know, but they should wear proper gloves anyway; but as a responsible person, I felt I should let them know. The reaction was very severe, they were horrible to me and didn't want to go near me, and that dentist put a big huge sticker on my file which she gave to some dental staff who wandered into the waiting room, with that big sticker saying 'HIV-positive' all over my file". Job [person infected with HIV]

"I was at the dentist, I had an abscess, and on the referral form I put down my medication. I went to see the dentist and he looked in my mouth and said: 'I am sorry, how long you have been HIV-positive?' I said: 'Since 2004, it is three years;' he said that he would not treat me anymore. Now he said he was going to refer me to [dental hospital], but I never received the letter". Julius [persons infected with HIV].

Medical practitioners also reacted by breaking confidentiality (disclosing HIV status by displaying red HIV stickers on their files, or talking openly about people's status in the hearing of other patients). For example, Julius and Job [persons infected with HIV] respectively reported that:

"Now another case of discrimination, I came down with scleritis back in 2006 and it damaged my right eye. So I was rushed into hospital where they did many tests and the optician looked at my records and said: 'HAVE YOU GOT HIV? HOW DID YOU GET THE HIV?' [Interviewee's emphasis]. I turned around and told him it is none of his business; if he had a problem he could refer me. This optician didn't have to ask where I got it and how I got it. Well it was not in a closed office, there were people walking down the side. He disclosed something straight away in the hearing of some patients walking around as well, and I didn't like that kind of idea ... when it comes down to medical matters, you get discriminated against for having HIV/AIDS. You can get discriminated from any kind of source, from the public area, even at hospital. Sadly people don't have any information about it [HIV] and approach it from a negative point of view".

"I was given a prescription and went to the outpatient pharmacist. The law is I shouldn't have to pay for my prescriptions. I took my prescription to the pharmacy, and I was asked to pay for my prescription. And I said that I don't pay for my prescription and they said: 'Do you have a card saying that you don't pay? Why don't you pay for your prescriptions?' I said very clearly that I was not prepared to discuss this in front of 50 people in the waiting room. I said I would write it down. So I wrote it down and passed it over to them; I was very, very embarrassed because I had come over with my work badge on, with my full name and a photograph on. Um, and that note was passed on to somebody and she argued with me in front of these 50 people about the fact that I should be paying for my prescription, and she spoke loudly saying: 'Well, if you had an HIV prescription from ['X'-floor] then you wouldn't have to pay for it. But this is from [Name] Dental Hospital'. So she broke

my confidentiality and I was absolutely devastated; I was just totally horrified that this pharmacist just disclosed my HIV status”. Job [person infected with HIV].

Discriminatory behaviours by medical practitioners to PI/A HIV/AIDS were not only distressing, and embarrassing, but also made them feel isolated and discriminated against. For example, Hope [person infected with HIV] also shared her experience:

“I experienced isolation and discrimination in hospital. Like in this other hospital I went to, they put a red star on your file that they should take care when they are handling you. That means you are HIV-positive so they need to be careful. So they just put a star, a red one; be careful, the person you are handling is positive. When you see that you say: ‘Oh God!’ ... I asked them what that red star was for. They said that it is sign of danger. You see! I said: ‘Danger, what do you mean?’ They said you have got some complications; I said: ‘Alright, so I am dangerous?’ They said: ‘No, you have got something.’”

Section 6.3.3 has provided insights into stigmatising and discriminatory practices in medical services that the respondents experienced. It was interesting to learn that different medical practitioners acted differently when it came to providing medical attention to persons infected with HIV. Discriminatory behaviour by medical practitioners was not only distressing, upsetting and, disturbing to a person infected with HIV, but was also unacceptable because medical practitioners were expected to take universal precautions, and to be sensitive to the feelings of their patients. This raised questions about the availability of universal health and safety precautions.

As discussed in the narrative, health worker’s insensitivity about their patient’s feelings made it extremely difficult for some patients to use health care services freely. Details of the relationship between discriminatory behaviour in medical services and HIV information behaviour are discussed in Chapter eight. Its implications on practice and policy are highlighted in Chapter nine.

6.3.4 Physical, verbal and mental abuse from family, friends and the wider community

The respondents reported that the most unpleasant prejudice they experienced was from family, colleagues, and schoolmates:

“I don’t feel comfortable with family around. [Hum] Because you feel that they are scrutinising you, they are looking for any signs of deterioration, and the last thing you would want is to have your family worry about you. My brother actually turned round and said: ‘Prepare for your own funeral’.

That wasn't very good from my brother. He was drunk at the time, but that put me in an awful situation; there was a point when I walked 14 miles home because he upset me so much. So me and the relationship with my family it is on the borderline, really". Julius [person infected with HIV];

"...when I was in a meeting with my team leader she worded it in such a way that I cried all day at work. Sorry, Robinah, I did my job all day, and when I went home, because of the pain in my mind, I just burst into tears. Actually I was in tears all that Tuesday night. The problem is that people such as those at my place of work, think that they have every right to say to anything to anybody. Those are issues that need to be addressed, and I think they could be prosecuted for careless speaking". Julius [person infected with HIV];

"Like at school, you know, nowadays it is all about your mom. Children start saying stuff about your mom and you don't even know them. At school, the insult is they say something about your mom but they don't know your mom. They will say: 'Oh, your mom is this and that'. And one of them said: 'Oh, your mom has HIV, so I hit them. I slapped him across the face". Jess [person affected by HIV].

In other cases, respondents complained about physical abuse and rejection by friends:

"...After my diagnosis, HIV affected me directly because I was rejected by my friends. That is, negative social networking. I experienced physical and verbal violence. I was in a shared house, people found my medication in my room, they kicked off and they found out what it was used for; they roughed me up, threw me out of the house. They believed I was a threat to them. I put my case before the police, but because of the moral judgment that goes with HIV, the police treated me as a criminal. The men remained in the house untouched. I must say that if I was a tropical bird living in a different country and was released in society, I would be attacked. They would verbally and physically attack you". Julius [person infected with HIV].

Fear of prejudice and discrimination from family, friends and colleagues resulted in persons infected with HIV keeping their diagnosis secret. Although the decision not to disclose the HIV enabled people to avoid discrimination, it could be detrimental to them as they may at times have no-one to turn to for emotional support, or confide in about the problems they may be facing.

The respondents also reported cases of prejudice and discrimination from the wider community which included physical and verbal abuse as well as harassment and victimisation from strangers. The reactions ranged from acts such as smashing of windows:

“People can be apprehensive; a friend of mine told me that when her neighbours learnt that she was HIV positive they threw bricks at her window”. Loy [person affected by HIV];

calling out abusive names such as ‘Grim Reaper’ – which implied that a person with HIV is reckless and seen as a death figure:

“There is a lot of victimisation. I have had people calling me names. They called me ‘AIDS carrier’; they called me a ‘slapper’, ‘male slag’ and things like that. They seem to judge it because it is got through two main routes: transmission through sex, and transmission through drug use or even blood products. But you can catch it from an assault. Because people will call anybody names: ‘smackhead’ or ‘junky’ because, when my health deteriorated, I was very, very slim and really withdrawn and looked like some kind of heavy drug user, which I am not. People called me ‘monkey’ because my body-mass index was below normal”. Julius [person infected with HIV];

“...because people these days assume HIV is dirty and it’s nasty; ah, you are just sleeping around. They say that it is a sexually transmitted disease and for one to get that sexually transmitted disease they must be sleeping around, and that makes you a ‘slag’ or something that is horrible. And it’s not all that. I... um they call you a ‘slag’ because you sleep around; they can call you someone who is dirty or a tramp. They say dirty, not like in clothes, but they refer to your way of life. I don’t like the way they talk because I say, you do not know anything. Because it is my mom who is positive, you don’t know what it feels like; you wouldn’t speak like that if you had someone in your family who is positive. That really hurt my emotions and feelings”. Jess [person affected by HIV];

to gossip and rumour-mongering:

“When you tell people, and you expect them to keep your secret, it is a very big secret to keep. You know it is very hard to tell a person unless that person is affected, or infected. I trusted somebody and that person betrayed me and told her children. You don’t tell children. And that child told my

daughter's friend. Because a friend has already told me that this boy is saying this about you. You know my friend who betrayed me [...] she thought it was her God-given right to tell somebody else. She thought that it was her responsibility to go and tell somebody else just in case they slept with me". Jane [person infected with HIV];

"... I am sorry to say that but ... [Name withheld] has told my friend that I am HIV-positive. I had not told that lady that I am positive. Since that time, my friend never called me again. She stopped calling me when she was told I am positive...that is breach of confidentiality. But you know, many people don't respect confidentiality. You would be told that that it is confidential but, even in hospital, there is no confidence in those people because they will say it". Fiona [person infected with HIV].

The respondents complained that the distress and stigma resulting from people's reactions was sometimes responsible for the ill health they experienced. For example, Job [person infected with HIV] reported that:

"...I have been very distressed by it and I will be again, I know I will be again, my mood fluctuates ... stress has an impact on HIV and that is a big thing to get across to people and one of the biggest stressors is stigma and discrimination. Um, that's other people's attitudes towards me. And they shouldn't be doing those things to me because they don't realise that they can make me ill. Just because you said something nasty, it's not finished. No, it is nagging at me, and it suppresses my immune system. You know, when you are stressed and distressed, your immune system doesn't function as well. People need to be responsible for their actions and behaviours because you never know how it affects other people... they need to see things from other people's perspectives".

Although prejudice and stigma were serious threats to living normal lives, this study revealed that it was very difficult to wipe them out of society completely, because some people could be naturally prejudiced. This knowledge was important PI/A HIV/AIDS to be able to face life boldly irrespective of other people's reactions to them. HIV/AIDS related prejudice was compared to racial prejudice:

"...Well I mean, you can compare it with racial prejudice. I mean you confront me and you are black. Based on the fact that the colour of a person's skin cannot be hidden or denied, [hum] and therefore you can't avoid it, so you have got to come to terms with it. If you are totally prejudiced, as soon as you see a person who is not the same colour as you, your brain is going to be thinking negative things, depending on how prejudiced you are. And how do people who are black face up to the world, without having to hide it, and they have the confidence to do it. I mean, it is awful this, do you understand what I mean? You can't hide it therefore you have to deal with it. Likewise people who are HIV-positive should come to deal with it". Angela [person affected by HIV].

6.3.5 Summary

Subsections 6.3.1- 6.3.4 described arbitrary negative reactions, such as cruelty, intolerance, dislike, and moral blame, which respondents experienced from other people. Respondents reported suffering not only from their own perceptions of who they had become (Goffman 1963; Alonzo and Reynolds, 1995; Frable et al., 1997; Helman, 2001; Colbert et al., 2010b), but also from other people's negative and unkind reactions to them. This was a source of some of the misery they experienced (Alonzo and Reynolds, 1995; Zhou, 2009; Colbert et al., 2010b).

Similar experiences are reported in previous studies such as Reis et al.'s (2005) on discriminatory attitudes and practices by health workers toward patients with HIV/AIDS in Nigeria; where health providers not only perceived treating persons infected as a waste of precious resources, but also did not always practice universal precautions and favoured restrictive policies towards people infected with HIV/AIDS. Similarly Zhou's (2009) study on help-seeking in a context of AIDS and stigma ... in China, reported that the impacts of perceived discrimination by health workers against patients were destructive. Zhou's (2009) participants complained about explicit discrimination such as physical avoidance, over-interest in their infection modes, and verbal insults, as well as subtle negative attitudes such as coldness and neglect. Arguably other people's insensitivity to the feelings of persons infected with HIV, particularly in the medical professions, could not only make it extremely difficult to use health care services consistently, but could also discredit, taint, socially label, and radically change, the way individuals view themselves and are viewed by others.

6.4. Conclusions

This chapter described the complex post-HIV diagnosis reactions experienced by respondents. It painted a picture of the emotional distress experienced by persons infected with HIV, and of the insensitive reactions from family, friends, medical practitioners and the wider community.

The chapter identified typical post-diagnosis reactions ranging from 'shock and emotional rollercoaster', 'shame, guilt and self-stigmatisation', 'worthlessness', 'feelings of loss and grief', loneliness and isolation, 'fear and stress', and 'denial', to 'coming to terms with

HIV/AIDS'. Making a personal choice to live life positively irrespective of other people's perceptions about them was identified as being an important step in diminishing the emotional distress posed by HIV/AIDS.

The chapter went on to explore reactions by family, friends and the wider community towards PI/A HIV/AIDS. These included 'perceiving persons infected with HIV to be a source of contagion', 'making value judgments', 'and discriminatory reactions by medical practitioners', as well as 'physical and mental abuse'.

From the post-HIV diagnosis reactions by other people described above, it can be inferred that persons infected with HIV experienced prejudice and stigma from a societal and a medical point of view. Whereas society exhibited tolerance to people experiencing illness such as cancer (which in some cases are a result of excessive smoking and drinking), persons who contracted HIV were not readily accepted by society. Society's preconceived perceptions about HIV were manifested in acts and reactions which endangered the status of persons infected with HIV, and compromised their acceptability in society. This study suggests that stigma could isolate the individual from self and societal acceptance, thus making living with HIV extremely complicated and difficult.

Arguably, ascribing moral blame to PI/A HIV/AIDS could undermine attempts to offer persons infected with HIV the care and compassion they ought to have. This study suggests that stigma not only compromised the quality of lives of persons infected with HIV, but also became an obstacle to prevention and management of HIV/AIDS, because it created an illusion among other members of public that they are safe. Attaching a mark of disgrace to the reputation of persons infected with HIV not only resulted in stressful emotions, but was also responsible for emotion-focused information strategies such as avoiding, hiding and destroying information (as described in Chapter eight) that people adopted in order to safeguard against other people's reactions.

The implications of the post HIV diagnosis reactions for the design and implementation of future HIV/AIDS-related information interventions geared towards the prevention and management of HIV will be discussed in Chapter nine.

CHAPTER 7- RESULTS PART 3:THE INFORMATION WORLD OF PERSONS INFECTED WITH HIV/AIDS

7.1. Introduction

Chapter six described post-HIV diagnosis reactions and argued that an understanding of these reactions could inform the design, management and delivery of HIV/AIDS-related information. Chapter seven (the third part of the results) focuses on the information world, also known as the ‘lived information experiences’ of persons infected with or affected by HIV (PI/A HIV/AIDS). In the context of this study, the HIV information world is composed of HIV/AIDS-related information ‘connects’ and ‘disconnects’, and information resources as understood and described by, PI/A HIV/AIDS. This chapter provides insights into the ‘lived information experiences’ of PI/A HIV/AIDS, including the dilemmas, frustrations, information ‘disconnects’ and ‘connects’ that directly or indirectly influenced their interaction with, access to, and use of, HIV/AIDS-related information.

7.2. Information resources

Section 7.2 discusses the HIV information world, information resources. The analysis identified a wide range of resources, including the Internet, information directly from people, printed information, the media (e.g., newspapers and television), HIV support groups, HIV clinics; and conferences, seminars and workshops, from which HIV/AIDS-related information was accessed. Thus sub-sections 7.2.1- 7.2.7 explore the varied information resources the respondents accessed and used to satisfy HIV/AIDS-related needs that arose from a positive HIV/AIDS diagnosis.

7.2.1 The Internet

Respondents used the Internet to acquire the information they needed to face the challenges posed by HIV. The analysis revealed that people turned to the Internet for a number of reasons, including gaining knowledge about the disease itself, the routes of transmission, and to obtain emotional support:

“I found out [that my dad is positive] when I was 14 [years old]. ...you know little booklets and the Internet were my main sources of information. The Internet has also provided some information on the emotional side of things as well. I think the Internet is both a liberating and a constraining source, but as a young person it was the easiest thing for me to access”. Sarah [person affected by HIV];

“.... as information became more available through the Internet, then I started to use that as a source of information. I still have them [information from the Internet] on my computer now, even though I don't use them. I suppose in the last five years [2005-2010] there has been much more information on the Internet. When I was emotionally ready to access information, it was very helpful”. Job [person infected with HIV];

“Libraries? NO! Internet, Internet, Internet. I mean there is nothing available in Libraries. I don't use libraries, period”. Justus [information provider].

Despite its tremendous potential for providing information, the analysis of the data suggested that the Internet could also potentially be a source of misinformation, especially for people who may not be aware of the official HIV/AIDS databases and websites:

“I think if you get the right information, the right website, it's great. The problem with the Internet is that there is also very poor and damaging information and people do believe it. For instance, there is a lot of information about cures for HIV, and that always worries me because there are so many people, especially those diagnosed early, who will look for information and this kind of thing affects them, they get misled by that kind of information. I mean the NHS website, the NAM website, the Terrence Higgins Trust (THT) website, are all very good; I mean, if you type 'HIV cure' in an Internet search engine it will produce a number of results, so that worries me”. Jack [information provider].

The respondents complained that the Internet could sometimes promote unacceptable behaviours as well as racist and sexist tendencies, and return undesirable results:

“...what has absolutely transformed the modern world is the Internet. And there are good things about this, and there are bad things about this. It is very hard to regulate what information is out on the Internet, and for me as a mental health professional, there are some absolutely terrifying websites which I would like to see shut down. Websites that promote anorexic behaviours; there are also really ignorant prejudiced websites, which are massively racist and sexist; you know the KKK organisation in America, they are repulsive, they are disgusting; what is frightening is the Internet is completely un-regulated”. James [information provider];

“...when you go on the Internet it is very stupid, in one sense, because whatever you put in you may get something totally different. I put in something for dogs and it came up with a pornographic site, you know women’s breasts there and I said: ‘Oh my God, this is not what I want. I am at work, I could get done for this.’ And you know, you can find out a lot of disinformation from the Internet. You know, it is a worry”. Job [person infected with HIV].

Respondents also complained that information on the Internet could be outdated, inaccurate, too technical and excessive:

“Some information is out of date. Information that is uploaded on the Internet is not regulated so you cannot be sure of the accuracy of the information. On the other hand, professional sites like AVERT and CHIV sometimes provide complex information”. Susan [information provider].

“Information on the Internet is too much, and you don’t know if it is true or not, because if you type ‘HIV’ you get thousands of information hits, and some are outdated; you don’t know who to trust. Information on the Internet is very hard for someone who doesn’t know how to search the Internet, if they type ‘HIV’ in [Google] the information they get may be overwhelming, scary, and sometimes too hard to understand. And some is wrong, with wrong statistics, you know”. Susan [information provider];

“They come in and say: ‘You know what, I went on the Internet when I was diagnosed and scared myself to death’, because they are quite naive and don’t know what to specifically search for, so they often end up being scared. So we say don’t believe anything you see on the Internet, it may not necessarily be valid, other than the major sites. Sometimes you open sites and you find information from the 80s still running. I mean [...] informal websites, blogs, TV, magazines, newspapers; you know some of the information there won’t be correct. Even a well-researched article can have discrepancies; if they got their information from a source which is old, then the information is going to be old too, and people who read it will read old information”. Claire [information provider].

Other people had a phobia for computers and considered the Internet dangerous, regardless of the nature of the information it provided:

“I don’t like it. I just find that computer stuff cannot sink in. It will not sink in. I don’t know if I have blocked my brain off, if I have a mental block; I say my brain is no good at that. And any information I want I will find it in the library. ...Internet... it’s a dangerous thing”. Jo [person infected with HIV].

To summarise: the analysis of data suggests that, although the Internet could potentially provide HIV/AIDS-related information, its value could be greatly undermined by the misleading, excessive, inaccurate, racist, sexist, and undesirable results people retrieve

from the Internet. The potential effect of undesirable search results from the Internet on HIV/AIDS-related information behaviour is discussed in Chapter eight

7.2.2 Information directly from people

The analysis of the data identified a wide range of groups of people, including HIV-positive speakers (expert patients and high profile HIV-infected people), friends and colleagues, and medical practitioners, who constituted invaluable sources of HIV-related oral information. Respondents reported that speaking directly to people who had experienced living with HIV, or had direct involvement with HIV, yielded very useful information:

“Most of my information has been from friends. A lot of it is word of mouth information; you tend to find it in positive meetings. They will be people who are positive, those who do not worry too much about it and they will get information from the Internet; then you will find expert patients, and they really, really know about it because they do investigations. In the middle are a lot of people who get information from these groups of people, and a lot of people who have encyclopedic knowledge about HIV/AIDS. So a lot of my information comes from people like that. I mean, there is information on the Internet, but unless I am looking for something very, very specific, I will use the network of people I know”. Joel [person infected with HIV];

“... I haven't read anything. My information comes from listening to persons like [name], [name] and [name of HIV-positive speakers] and [name of support worker]. My understanding has increased phenomenally through that. I hadn't realised properly until the first time I was with [name] and heard him talk that really [daughter's name] could be alive today”. Angela [person affected by HIV];

“... but predominantly it was face-to-face contact with medical people. I was meeting them regularly every six weeks, and also getting information from my social worker. They were the main sources initially of information about my HIV status. Another big source of information about HIV infection came through high profile HIV-infected people, like Freddy Mercury. He was a very significant person in my family; all of my family was very big fans of Freddy Mercury, and there was a perceptible difference in their attitudes and ideas about HIV after it became apparent that he had died of HIV/AIDS; and I think that was a turning point in my family and their understanding”. Job [person infected with HIV].

The data analysis revealed that information directly from people could make more of an impact because it was perceived to be knowledge gained from first-hand experience. Thus it appealed to respondents' feelings, and provided face-to-face interaction with the actual person:

“From my experience of working at [Name of HIV support group], and also as a person [infected with HIV], I think it is talking about peoples' life stories, how people are affected by HIV, and how they are living with it. That has more of an impact on somebody because basically you can see the person face-to-face; i.e., you can sit down and have a one-to-one with somebody. Positive people in a doctor's waiting room can have a chat and share your stories. This is what can have an impact other than literature. Literature is good; I am not saying that you should not read it. I am saying it has its place, but people information is a lot better. It is the inter-link between ‘Oh, that's an actual person, this is not a picture, and he is a real person’; and that way it clicks in a bit. You get that interaction. ‘Oh by the way, I was diagnosed at such and such a time, I was given two weeks to live;’ [...] it clicks in much better than reading a book”. Luke [Information provider];

“One of the big things I think was significant to me, because I didn't speak to another person knowingly who was HIV-positive for five years. And it's only five years ago when I started being involved with [Name of HIV support group] that I actually knowingly spoke to another person who was HIV-positive. And although their experiences are totally different, being able to speak to another person who has some comprehension of what it is like to be HIV-positive was very, very, very helpful. And this is one of the main reasons why I do the work I do for [Name of HIV support group], going into schools, because I think actually speaking to young people as a person with a story to tell, has much more impact on them than any amount of textbooks or leaflets”. Job [person infected with HIV].

The data analysis also revealed that information directly from people in a friendly and informal way, often in an informal environment, made learning about HIV less threatening and more reassuring as people talked about HIV without fear of being judged or stigmatised:

“One of my doctors used to take us to the pub; we used to go and discuss things. He said: ‘Look you can drink but you cannot drink very much, you will get hepatitis B in your liver.’ But I mean he was creating an environment where you can chat, and trying to impart the information. You know, it would really sink in; I mean it is not very official, it is like you are friends, you are chatting and he tells you what is good and bad for you. He is not giving you booklets and leaflets”. Amos [person infected with HIV];

“You need someone to talk to you then you get it. But to read it, you just go through it, 1, 2, 3 and you are done. You know, others don’t even understand what is happening; they need people to explain it to them, so they will get it.... but they say ‘what you see is what you get’; in the same way ‘what you hear is what you get’. If somebody stands there and starts explaining it, that is what you get. But for you to go home to start reading, you have a TV there so you will not read. But if you meet with someone such as a counselor, they will say $1+1=2$ and you get that information”. Hope [person infected with HIV];

“I have learnt a lot through talking to some public speakers who come to [Name of HIV support group]. I listened to their life stories and asked questions and shared their experiences. [...] So I got much of my information from talking to people. That is one of the things which is useful about this place [Name of HIV support group]”. Rose [person infected with HIV];

“That is why positive speakers are very good. We do go to hospitals because there we can speak to somebody and ask how did it feel when you went to hospital? What were the issues you found when you were in hospital? It helps them that way”. Rita [information provider].

Although data analysis suggests that information directly from people was invaluable; a number of criticisms against people as a source of information were also identified. For example, information directly from HIV-positive speakers, was criticised on the grounds that such speakers lacked the moral authority required to disseminate HIV/AIDS prevention information:

“I understand that it is really, really effective when HIV-positive people go out into communities to talk about their experiences. But sometimes, the way I see it, sometimes it may have the opposite effect. Because if somebody who is positive comes and speaks to me, my idea would be like: ‘Well, you did this and that is why you are positive; I am not doing that! I am not gonna be positive.’ But if somebody who is not positive comes and tells me: ‘Right, look you should be careful, you should avoid risk,’ I would quite understand; because from my point of view if somebody who is HIV-positive comes and talks to me I will say: ‘Oh, they are comforting themselves by talking to other people, telling them they are positive’; that’s how I see it. I think that is also a grey area”. Mary [information provider].

In addition, unique individual circumstances sometimes could render other people’s experiences irrelevant:

“They give me information about their circumstances and sometimes people are on the same medication as me but they are older than me, or they were HIV-positive a long time before having medication; so the fact that they are having the same medication as me has limited value because it is very, very personal how your medication affects you. It affects you as an individual. Rather than

getting new information from other people who may take [the] same medication as me but their history is not the same; their health history is totally different. What they have been exposed to in their life is totally different; the viruses and infections they have been exposed to in their life is totally different from me. So you can't transfer information directly from them to me. So checking with other people that work at [name of support group], sometimes that has been a good thing, sometimes that has been a bad thing, because the people I have talked to are in a different place than I am in regard to my HIV status". Job [person infected with HIV];

"We have Positive Nation [booklet] where we read about people's stories on HIV but you know that is no guidebook at all. Everyone is different". Julius [person infected with HIV].

The data analysis also revealed that, despite the depth of information obtained directly from people, there was fear that such rich and useful facts could be lost because such information cannot be easily preserved for posterity:

"It is a difficult subject to have people who have incredible knowledge about HIV. I know one guy who is an encyclopedia on pain-killers. You can ask him anything on pain-killers and he knows the answer to it. It's sort of oral traditions – word of mouth. Hopefully they will pass on knowledge that way. I would like to see part of that knowledge preserved. I think that would be a fantastic idea; I mean there are a lot of people out there who won't talk openly about their lives; if you could use it as a resource, people would look at how it is to live with HIV from the point of view of someone who has got HIV". Joel [person infected with HIV].

Sub-section 7.2 illustrated that respondents felt information directly from people could potentially have great impact because it accorded people an opportunity to interact with, and speak to, people with comprehension of what it means to be infected with or affected by HIV/AIDS. The practical and simple style of delivery of information, particularly other people's experiences of living with HIV, could make living with HIV less taxing and threatening. Some respondents felt information directly from people could sometimes be perceived to be less authentic or irrelevant, depending on the audience it is presented to and the source of the message. Section 7.2 has unearthed merits and demerits of information directly from people which might otherwise be taken for granted. Details about the relationship between style of information delivery and information behaviour are discussed in Chapter eight.

7.2.3 Printed information (books, booklets and leaflets)

The analysis of the data showed that printed information in books, booklets and leaflets such as *Living with HIV*, NAM booklets, *Treatment updates* and the *Positive Nation* played a role in providing the information the respondents needed to answer numerous queries that arose in the course of living with HIV:

“You know this book *Living with HIV*; it is the best book I have ever read. It tells you exactly what you need to know; I was a heavy drinker before, and I needed to know how to avoid doing damage to myself. At the clinic they have these little booklets. I find them quite useful. And I just read about it [HIV]. When you read about it, it tells you load of information about HIV/AIDS-related illnesses”. Jane [person infected with HIV];

“The Positive magazine, magazines that talk about treatment, how to look after yourself and magazines that talk about life experiences of people who are HIV-positive are very useful”. Sam [person infected with HIV];

“There is a science text book. I read it and it said it is a virus that gets in the cells and just takes them over and how taking medication tries to get rid of it. It also said that, if you don’t take the medication, it becomes resistant”. Jess [person affected by HIV];

“Well, the book they gave me here [Name of HIV support group] had a lot of information on HIV and I read and I learnt quite a lot from it. The Positive magazine, that is quite good”. Jo [person infected with HIV];

“I think these are really, really, very useful, these kind of booklets. When I go to X-floor, there have just been some new booklets that have come out about HIV and your body, HIV and your bones, HIV and your kidneys, HIV and your body shape, HIV and your CD4 count, HIV and your liver, HIV and your check-up, and I think specific literature like that has been helpful for me to be aware. I like the way they are presented, because they have just got a mixture of people on the front and I think that is very, very important. I mean, I have just picked up these two magazines. I mean Positive Nation, it’s got a group of African people on the front, and the title is ‘Clayton goes to Ghana’. But there is also something about ‘walk for life’ which is about fundraising. There are all sorts of things here. Just looking through, there is a variety of articles which I find useful”. Job [person infected with HIV].

Although the findings suggest that books and booklets are perceived as valuable sources of information, they could be inappropriate if they are written at the wrong level, or if people are unable to read at all. Some respondents complained that reading difficulties, or the

language barrier, made books and booklets inappropriate for disseminating HIV/AIDS-related information:

“I have got issues with leaflets. If information is gonna be given out, I prefer talking to people face-to-face in the community; not everyone has the competency to read. If I look at Britain, it’s a multicultural society, we have got people from everywhere, and you cannot ignore the fact that some people living in Britain cannot speak English. To be honest, at the Terrence Higgins Trust (THT), all our leaflets are in English; there could be something in French, but you don’t get all languages targeted, that is where I am coming from. You give someone a leaflet, and they are unable to read it: it’s not always about the language it is written in; some people can’t read. We cannot deny the fact that some people cannot read, so giving them a leaflet, they cannot understand the terminology used”. Mary [information provider];

“You know, in my experience of providing information at [Name of HIV support group], leaflets are good, but they are also bad, because if I give you a leaflet, I don’t know your level of understanding. You can go on distributing leaflets about HIV but you don’t know the level of understanding on HIV. It could be complicated”. Susan [information provider].

Books and booklets were criticised on the grounds of not catering for certain age groups such as children and teenagers, providing out-dated information, or not being interactive:

“...to be honest, I haven’t seen any books for little children specifically on HIV. They are always for adults. I think they should make some for at least young adults, teenagers; they should make books on HIV for them. Many children would not read a big book. I think there should be some for teenagers and young adults”. Jess [person affected by HIV];

“I think the books are so old that you can misdiagnose yourself. And the situation can appear ten times worse than it actually is”. Jane [person infected with HIV];

“We’ve got the little NAM books and there is one on lipodystrophy and it said things like ‘the face loses fat’ and things like this. There are no pictures in the NAM booklets. I could not picture it. This was scary. Something visual would perhaps have been more useful to me when I was younger”. Sarah [person affected with HIV].

To summarise: although books are valuable sources of information, their value could be undermined if they are written at the wrong level, or if they are out of date and not illustrated. These limitations could compromise the value that could be derived from using printed information to satisfy information needs arising out of an HIV/AIDS diagnosis.

This subject will be discussed in Chapter eight, where the relationship between information ‘disconnects’ and information behaviour is examined in more detail.

7.2.4 The media (TV, newspapers and radio)

Although the respondents acknowledged the potential of the media as sources of information, the media did not appear to be providers of HIV/AIDS-related information. Respondents expressed concern about lack of information on the prevention and management of HIV in the media:

“The TV is not doing anything! There is nobody who has done a one-hour special with known persons on TV such as Piers Morgan; we need to have a new thing like Panorama, one of those great shows. If they would do something like that, a one-hour special, two or three one-hour specials, on one of those information shows just to target the general public and getting people to watch it, something like that would be very useful to sensitise the general public. I mean, imagine how much it costs for life-time health care. TV is the best medium, like a 30-second free public service commercial on the important points about HIV, and then play it again. And after two or three times when it has been on, it can be different information done in 30 seconds”. Ben [person infected with HIV];

“That’s why I said TV, because here people watch TV a lot. They can’t do without a TV at home. [...] just cut down on the EastEnders and put on HIV. People will listen. If you miss it one day and put on HIV instead, people will watch because they will be ready to watch EastEnders and this comes on, they will say: ‘Oh, let’s watch it.’ They will get the information. But they [Media] don’t have those adverts, nothing. [...] Newspapers? [...] that is the same thing. Newspapers here don’t do anything. I think the best thing is to have sponsors to put it on TV”. Hope [person infected with HIV];

“...um to be honest, I have not seen anything on TV about HIV”. Jess [person affected with HIV];

“I haven’t heard of much on the radio on HIV. They talk a lot about sexually-transmitted diseases (STDs), such as gonorrhoea, syphilis, Chlamydia; these are regularly mentioned on radio, but radio has never ever mentioned HIV and the problems it causes. I know some of these service providers have been on the radio and talked about HIV, but I haven’t heard of anything recently”. Julius [person infected with HIV];

“Here in the UK, there is not much information in the media, or at least I don’t see much. You can’t see that on telly [Television]. About HIV? I don’t think so. Have you seen some? All that you see is celebrities, this and that, but as for HIV they don’t put it on, I don’t know why. People don’t know anything about HIV; most of them are hiding in their houses”. Hope [person infected with HIV];

“HIV isn’t really visible in Britain today you know; it’s not on the news, not on TV programmes very often, and when you do see it, it is very much side-lined, like um, used to dramatise a storyline on ‘soap’. It’s not a main story line, [...] that is why the AIDS stereotypes of the 80s seem to be perpetuated. People are more reminded of being gay or sexually deviant, and so the fear still exists because it is not publicised”. Claire [information provider].

Respondents were also concerned that HIV only featured in the media for fundraising purposes, or if a celebrity dies from AIDS, or for World AIDS Day celebrations.

Disseminating HIV information in a sporadic manner could hinder efforts towards creating awareness about HIV/AIDS in the UK:

“How often do you see HIV/AIDS in a newspaper? Only when a celebrity has died from it. If a celebrity has HIV and dies from it, it will make headlines in the newspaper. As a positive person and a person who works for the support group, the only time that HIV and any other disease such as malaria and TB is mentioned is when they are fundraising. If you noticed, the other week for Sports Relief, celebrities went and did something sports-wise. We have these celebrities go out into the community, whether it is in India, Africa, or England. They say: ‘This is a child and her parents are positive but she needs to be looked after.’ This is when it is on the media. So that is only when people see it. I would say this is a disease which is here 365 days a year. Yet the only time that it ever hits the headlines is at the end of November-December time when everybody wants to get the statistics of HIV, to talk to somebody who is HIV-positive”. Luke [information provider].

To summarise: respondents expressed concerns that, despite the mass media's potential to reach large sections of the population, it was not perceived as beneficial to the HIV/AIDS cause because of the tendency to disseminate incorrect information about HIV. Instances when correct information was disseminated were discontinuous and isolated, so that few tangible benefits could be realised. This raises the following question: can we infer that the media in England may possibly not be operating at optimum capacity as far as disseminating HIV/AIDS related information is concerned?

7.2.5 Conferences, seminars and workshops

Conferences, seminars and workshops were not only an avenue for accessing reassuring information that P/A HIV/AIDS needed, but they also provided opportunities for sharing personal experiences and learning about HIV directly from people with expert knowledge about HIV/AIDS and /or had experienced HIV in their lives. Conferences were often a useful source because they provided a forum for interactive group-learning:

“When we went to the conference in Leicester, the hall was full of HIV people from the all over the world. Another lady stood there and said she was a doctor but she was HIV-positive. [...] that is when I stopped worrying. Some told us when they were diagnosed, and they were still carrying on taking their medication. [...] It is when we started learning that you should not skip your medication. You should take your medication as directed by your doctor and not take any other tablets”. Sue [person infected with HIV];

“...we have seminars here at [Name of support group], people come from London to teach about HIV, and then you could ask all the questions you want to have more information on about HIV”. Jo [person infected with HIV];

“So regarding information, I used to go to [HIV support group] and these people used to come and inform us. They used to come and give us lectures in the women's group mostly. We frequently got people from different areas that used to come and give us lectures about our condition. They really used to help us. They paid attention to the medication, [...] and to routes of transmission. If I am positive and I have a partner who is not positive, how I should communicate with him, or else he will catch the disease”. Fiona [person infected with HIV];

“I would quite like to do more workshops, because we have a guy who comes in to do treatment updates and pass on information. I am gonna get a dietician and a Genito-Urinary (GU) or Genito-Urinary Medicine (GUM) clinics person, and they will give information face-to-face because I think that has far more impact for our clients; those that have language problems and can't read as they would want to, can take part. We have had one workshop where we started with basics such as CD4,

then go onto employment, diet, nutrition, dentists, stigma, etc. That is quite useful because people can go through the information together as a group, learn from each other as a group, in a safe environment here [name of support group]. You know they can say: ‘ I don’t know what this really means, I found this hard, things like that, or what do I need to do at my work place? Who do I need to tell?’ So I quite would like to do more workshops. I don’t need any more written information, I don’t need any more books; I need these people to come and do workshops”. Rita [information provider].

Respondents complained that although conferences, seminars and workshops are a valuable source of information, they are generally only open to medical specialists, people with close involvement with HIV/AIDS, such as experts and people suffering from the disease. They suggested a need for events that are open to members of the general public.

“If there are any conferences they are not open to the general public. There is a World AIDS conference which is held in different cities around the world. And it is designed for HIV specialists, people that are involved in the HIV/AIDS fields, such as pharmaceutical companies, the practitioners involved in HIV, the social workers, and the support groups. If it was more open to everybody else out there, you could invite leading people in the surgical world, GPs and people like that, and say: ‘Ok then, this should be common knowledge for you,’ because there are HIV-positive people that are going to see the GP”. Joab [information provider].

The analysis has demonstrated that although conferences, seminars and workshops could potentially create awareness about HIV/AIDS, there are drawbacks because these are often not open to members of the general public. This could also account for the widespread lack of awareness about HIV among members of the general public.

7.2.6 HIV support groups

The analysis of the data showed that HIV support groups are perceived by respondents as an invaluable source of HIV/AIDS-related information. They not only provide access to a wide range of sources of information (such as books, booklets, information directly from people as well as from the Internet), but also provide a conducive environment for people to access and use information without any fears of being judged and/or stigmatised. The statements below were selected to illustrate that HIV support groups could be vital sources of information for PI/A HIV/AIDS.

“My dad was told that there was a guy where we lived who was doing a support group. He went first, and then I met the guy who was running it. I started coming in and well, I have been here ever since. You know it has been a kind of process for me because I have grown up with [name of support

group]. It has really been a place where I found information, I've gained experiences". Sarah [person affected by HIV];

"I come to an organisation such as this one [Name of support group]; they have some books that come out every month, updating you. You see this HIV treatment update [respondent shows interviewer the booklet]; they have a conference in America, [...] they come, sit down and they write all that information down, then they distribute these books to the HIV groups so that people will have the information quicker". Rose [person infected with HIV];

"This place [Name of HIV support group] is brilliant. It has helped me so much, it has got access to basic things such as [information] . I almost hit my daughter because she used my toothbrush. She didn't know I was HIV-positive, so when she used my toothbrush I thought I had passed it on to her. I was thinking all the time I would pass it on to her. So I had to stop all these things, and eventually she had an HIV test herself, only because I might have passed it on to her". Jane [person infected with HIV];

"[Name of support organisation] has many booklets that relate to many issues affecting people with HIV. Such as books that deal with mental health, stress, depression, and anxiety. There are booklets for people who have been newly diagnosed. What they go through is that denial time where you deny things: 'No, maybe it is not right;' and then guide you through the choice of medication; then you start taking medication, and it is not as simple as taking as paracetamol". Monica [person infected with HIV];

"[HIV support group] people know what they are talking about, everything to do with what medications are working in the body, why it is so important to take them at certain times, because you need to know why it is important to leave 10-12 hours between these pills. They teach you what the pill does. Like what it does in two hours, five hours, and why it is so important that when that pill stops working then you take another one to keep a level of this pill in your body. That is very good information because you need to know that before you can start taking the pills, because it is for the rest of your life". Jane [person infected with HIV].

The data revealed that the HIV support group was not only an avenue for accessing a wide range of sources of information, but it could also provide a forum for PI/A HIV/AIDS to learn about HIV/AIDS and share experiences of living with HIV with colleagues:

"When I came here I found it easier because in a group like this, people who are all HIV gather for a coffee morning discussing, and you will be able to talk to each other about your condition. We get information from one another, sharing the information". Rose [person infected with HIV];

"Then I went to [Name of support group] regularly. It was a friendly place where we used to meet and have lunch, have tea and coffee. Apart from maybe when someone was coming to teach us

something about HIV, like you saw that guy who came and talked to us about the importance of taking our meds regularly. That is how I got information. ...we had people coming in, you know like to this women's group, people were coming in, teaching us about HIV (how we cannot transfer it to another person, how we can avoid other people getting HIV). That is how I got information". Fiona [person infected with HIV].

The analysis demonstrated that HIV support groups could play a vital role in disseminating HIV/AIDS-related information through HIV forums such as workshops, seminars and regular group meetings. Such forums could enhance interaction with HIV/AIDS-related information and create awareness about HIV. HIV support groups also provided a forum for meeting people with similar experiences. The opportunities the HIV support group premises provided for people to seek and share HIV/AIDS-related information are discussed in Chapter eight.

7.2.7 The HIV clinic

The data analysis also demonstrated that the HIV clinic was a trusted and highly regarded source of HIV/AIDS-related biomedical information, and other forms of information that most respondents needed:

"I gained a vast amount of the information I needed from the [HIV] clinic where I went on a regular basis during my consultation sessions. [...] Initially it was purely and simply from the medical doctors at the clinic; ... there was just the 'X'-floor of the [Name of hospital]. That was the medical information. They gave me drug information about what the drugs were that I had started". Job [person infected with HIV];

"I was allocated a special HIV doctor who said: 'I have people who are worse than you, but after receiving treatment you will bounce back to your life. HIV doesn't mean you've got AIDS. HIV is a disease which can lead to death if untreated. So you have a good CD4 count which means you have a good life expectancy. Don't worry about anything. If your CD4 count – that is to do with your immune system – goes down below 200 we will start on treatment that will be able to make your immune system go up again.' So, if you continue being yourself, things will move on". Monica [person infected with HIV];

The analysis demonstrated that information from HIV clinics was perceived as trustworthy. For example Job [person infected with HIV] reported that:

"For me, any new information I get about being HIV-positive, I check with my doctors. I have been treated by the same professionals for the last 11 years, I trust them implicitly. I know that the

department that I go to is very highly regarded in this country and it is one of the reasons I am staying in [Northern England], I don't even use my GP. I feel very strongly linked to the X-floor and the staff there, they have given me an enormous amount of strength. So when I have found out new information, I have checked it out with them".

To summarise: respondents felt that HIV clinics are an invaluable source of the trustworthy biomedical information needed to live with and fight the battle against HIV/AIDS.

7.2.8 Summary

Section 7.2 has demonstrated that the respondents accessed and used a wide range of information sources such as the Internet, information directly from people, books, booklets and leaflets, the media, HIV support groups, workshops and conferences during the course of living with HIV/AIDS. This finding is consistent with previous work such as Marin (1990), Lagarde (1998) and Pennbridge (1999), which investigated the array of sources and channels people use to access HIV/AIDS-related information.

The current study has also demonstrated that some sources, such as the media, were perceived to have great potential, but were operating below capacity because they did not disseminate as much HIV/AIDS-related information as expected of them by respondents. Books and booklets were perceived as valuable, but issues such as information being out-of-date could compromise the potential benefits to be derived from them. This finding is reinforced by Mehra and Dessel's (2011) study which reported that most of the books about HIV in the libraries studied were out of date.

On the other hand use of technical language was reported to undermine the value of information resources while information received directly from people was perceived invaluable in meeting social support information needs. However, criticism against information directly from people, such as lack of moral authority (in the case of HIV positive speakers) and difficulty with preserving oral information could undermine the usefulness of this source if not addressed. The analysis also demonstrated that although the Internet had great potential to provide the information that the respondents desperately needed, it was constrained by the presence of excessive, outdated, and undesirable information.

HIV clinics and HIV support groups were perceived to be trusted and useful for HIV/AIDS-related information by respondents because they not only provided forums for meeting people with similar experiences but they were also venues for a number of sources of information. The analysis also demonstrated that the sources were complementary to each other as different sources could be consulted at different times, depending on the kind

of information required. The current study has increased our understanding of the challenges, dilemmas and frustrations people experienced in accessing and using HIV/AIDS-related information by highlighting HIV/AIDS-information disconnects (see Section 7.3).

7.3. HIV/AIDS-related information ‘disconnects’

This section describes ways in which the nature of information resources shaped HIV/AIDS related information behaviour. In the context of this study, ‘information disconnects’ refers to aspects of HIV/AIDS-related information resources that make access to, and use of HIV/AIDS-related information challenging and difficult. Section 7.3 focuses on HIV/AIDS information ‘disconnects’, including barriers, dilemmas and frustrations that respondents experienced during the course of interaction with HIV/AIDS-related information resources. The disconnects included information being alarming, worrying, and upsetting; unavailability of information; excessive information; information written at the wrong level; stigmatizing and untrue information; and information implying that HIV/AIDS relates to deviant “others”. Sub-sections 7.3.1-7.3.7 below describe the information ‘disconnects’ in details.

7.3.1 Alarming, worrying and upsetting information

The data analysis revealed that many of the respondents experienced alarming, upsetting and worrying HIV/AIDS-related information. Biomedical information, particularly information on the side-effects of medication, and the effects of HIV/AIDS on the quality of life – especially possible physical and mental deterioration – could make people feel alarmed, scared, disturbed and frustrated:

“I could die from a heart attack. I could die from diabetes. I could die because my medication stopped working. [...] I mean, there is new information coming and the big thing for me that terrifies me absolutely is developing dementia sooner. [...] I find the various information on drugs frustrating and unhelpful. You know there are so many different research projects going on; there is so much information that it is a bit frustrating and unhelpful because you get very confused, and very worried because of contradictory information. You know the bottom line is, it is a new disease. It has only been predominant for 30 years”. Job [person infected with HIV];

“The worst information for me was the books that they give you. You read about the worst stages of HIV. It said when you get on medication you will suddenly get so ill. They talk about people who

have had it for so long. The bad experiences they have had. The books talk about that quite a lot". Jane [person infected with HIV].

The concerns of persons infected with HIV regarding HIV/AIDS-related information being scary, worrying and upsetting were reinforced by information providers. For example Justus [Information provider] reported that:

"We have clients who, when they read something, for instance one of them opened an article and read something which said: 'Increased risk of cancer from HIV medications' and he froze! Because he thinks that everything that can happen will happen to him. So he just saw this headline, increased risk of cancer, and he started sweating, worrying, and freaking out".

To summarise: respondents felt that worrying, alarming and upsetting information could be emotionally disturbing, distressing and counterproductive. Arguably, if people received alarming information they could be discouraged from accessing and using similar information in future. Chapter eight discusses the relationship between the information 'disconnects' and information behaviour in detail.

7.3.2 Lack of HIV/AIDS-related information

Lack of HIV/AIDS-related information was a 'disconnect' experienced by the respondents. The analysis of data has shown that PI/A HIV/AIDS experienced a shortage of HIV/AIDS-related information they needed (as discussed in Section 5.3) and to make important decisions:

"...I needed to know what the meds are gonna do. I couldn't find any of this information. I needed more information but I couldn't get it. I had to go through a lot of emotions and I wouldn't take the pill unless I knew all about that pill and all that it is going to do to me. That is what I had to fix in my head and it was really hard. Really, really, really hard". Jane [person infected with HIV]

"But time and again, I am tired all the time, absolutely tired and that confuses me because I don't know whether it is the diabetes, or my HIV, because with diabetes you fall asleep a lot. I don't know, I don't think there is enough [written] information at this place. It is only verbal". Belinda [person infected with HIV]

The respondents also complained about lack of up-to-date HIV/AIDS-related information in the media:

“... the newspapers and TV media are saying ‘lay down and take it, protect yourself first don’t get it’ and then there is no information after that. There is no information [saying] that if you get HIV it is sustainable; that is if you get it traced in time, and you’ve not let your body go down too far downhill. So with them they say ‘don’t get it, protect yourself.’ They don’t say: ‘if you have it start moving now.’” Jo [person infected with HIV]

To summarise: the analysis of data has demonstrated that respondents could experience difficulty in obtaining the requisite information to address day-to-day life issues. This finding suggests that improvements in the availability of biomedical information, psychosocial information and practical information could potentially improve the quality of lives of persons infected with HIV/AIDS. The effect of lack of HIV/AIDS-related information on HIV information behaviour is discussed in detail in Chapter eight. The next sub-section discusses important information disconnect in the HIV information world: excessive information.

7.3.3 Excessive information

Information overload was a major problem associated with HIV/AIDS-related information. Respondents complained of feeling overwhelmed by the large amounts of HIV/AIDS-related information, particularly on the Internet. They were distressed by too much, and often contradictory, information because it was difficult to work out which information to use. Respondents also complained that official websites also bombarded them with too much information. This sometimes resulted in their avoiding or destroying information. For example, Job [person infected with HIV] reported that:

“... I get my information from very reliable sources, official websites. I don’t get them from random websites but because there is so much information I subscribed to NAM HIV weekly, there is a weekly email that goes out with information, and as somebody with HIV, that is just too much information. So I now don’t look at that information, I delete it off my email. I emotionally panic and get distressed by new information. There is just so much information, it is too overwhelming”.

Too much information soon after the diagnosis was perceived to be frightening and dangerous to PI/A HIV/AIDS:

“That is the problem with information on the Internet. You may get scared from reading it. But if you find information that starts with the basics and then continues to complex issues, it can make

sense. I think it is dangerous to take pieces of information from here and take pieces of information from there, because you can come to wrong conclusions by reading it. Yeah, you cannot teach a five year old using material written for a 16 year old. There is need for some basic information to build from. Too much information too soon can be dangerous”. Justus [information provider];

“...The down side, or the negative side to information, is taking too much information – taking too much detail at once at the beginning of a diagnosis. It can be very frightening. It may also cause damage if you read things on the basis of which is happening to you”. Julius [person infected with HIV].

The analysis of data also indicated that HIV/AIDS-related information was not only excessive but it also changed frequently. This was frustrating both for information providers and service users who could not work out what the right information was:

“The booklets and leaflets, they send too many out too often. Update after update, the contradictions in the main articles that come out. That is not always great. Do you know what I mean? It’s quite difficult if you are giving out information that actually changes every now and again, and especially if it changes so quickly so soon”. Rita [information provider].

From the multiple voices above, it can be inferred that information overload is a serious hindrance to accessing and using HIV/AIDS-related information. Excessive information is not only frustrating to PI/ A HIV/AIDS, but can also make provision of HIV/AIDS-related information provision complicated.

7.3.4 Information that ‘others’ HIV/AIDS

In the context of this study information that ‘others’ HIV/AIDS refers to information that portrays HIV/AIDS as a disease characteristic of ‘others’ such as Black Africans, people who are gay, and prostitutes.

“For a long time it was on gay men. There has been a process of distancing HIV. So they are not actively talking about it. There are still moral ties attached to it. It tends to be attached to asylum seekers a lot, then gays”. Jack [information provider];

“...in my research I found a lot of images, when gay men are always represented in HIV magazines when they are naked”. Claire [person affected by HIV];

“Currently HIV/AIDS information is so targeted at groups such as Black Africans and gay men, yet HIV can affect anyone. There is this attitude that HIV is for ‘them’ and not for ‘us’”. Joy [information provider].

Respondents felt that information that ‘others’ HIV by perpetuating stereotypes could undermine efforts to fight HIV as people may believe it cannot affect them. For example, information portraying HIV/AIDS as a disease for people living in other areas could result in an illusion that groups of people who are excluded from HIV are safe from contracting HIV/AIDS:

“First of all it was passed on by gay people; heterosexuals took longer to get it. African people got it first; when it came to this country, I thought it was in London. You always thought it was somewhere else, or with somebody else. That was the feeling, it was somewhere else”. Jane [person infected with HIV].

Information with racial overtones including images of Black Africans on the front pages as well as inside in most of the documentation on HIV could lead to perceptions that HIV/AIDS-related information is irrelevant to other groups, and could make the dissemination of HIV/AIDS information to other people extremely difficult:

“...So people had the impression that I am British, the only people that I see getting HIV or AIDS are in Africa, or asylum seekers in my community. So, I am not a gay man, I am not an asylum seeker, so it is not gonna affect me!” Claire [information provider];

“The thing that is common with the information that we usually get is that there is always a black person on it or somebody who is gay. Where is the heterosexual white woman in all this literature? She is not there. You pick up any magazine, you go upstairs and pick up the booklets, and tell me if you find a middle-aged white woman shown on any of the information given. Maybe one, but not that many. How many people from South East Asia have you even seen in HIV information? How many people have you seen looking like an Hispanic from Brazil? How many elderly people. As I said, if you went upstairs now and had a look at the literature, it is a shame because this needs to be a campaign for everyone. You cannot discriminate against HIV, you need to include everybody in the information you give out, and otherwise people will say: ‘Do I have to read that? It is not relevant to me’. That is the other problem with HIV information – it is not necessarily relevant to the person you are trying to talk to”. Rita [information provider];

“Seeing documents mentioning Black Africans and HIV. There is no continent that has not experienced HIV. If you provide information for Black Africans in England, a country that also has Asians, Chinese how do you think you can plan only for the Black Africans? You realise that most of the magazines have pictures of black people and gay men. That makes other people think this information regarding HIV is not for them. You know, since HIV is now a global problem, it is not wise to target information to specific groups of people”. Mary [information provider];

“There is also an issue of the information targeting specific groups of people such as those involved in prostitution, the gay community, and African people. This is a problem because other people are then being ignored. Other groups may think: ‘that is their problem. It is not my problem,’ so they don’t benefit from the information. I think that is a grey area when it comes to passing information to other people”. Susan [information provider].

To summarise: information that portrays HIV/AIDS as a disease for ‘others’ could result in complacency on the part of other members of the community who consider themselves to be safe from contracting HIV/AIDS. Respondents felt that by ‘othering’ HIV/AIDS, information may not only undermine efforts to prevent and manage HIV/AIDS, but could also have negative effects on other members of the community, including exposure to risks of contracting HIV, and failing to take HIV tests, or seek medical attention.

7.3.5 Stigmatising information

Respondents reported stigmatising information as a major disconnect as far as HIV/AIDS-related information is concerned. In the context of this study stigmatising information refers to information presented with a manner, tone or message that assigns blame to persons infected with HIV/AIDS. Respondents reported experiencing information in which HIV/AIDS were depicted as a signifier of guilt:

“Oh, newspapers are saying all these ugly things regarding HIV; there has been a lot of bad press saying: ‘Someone has infected somebody else, they have gone to court and they are being sentenced to five years imprisonment’; it wouldn’t make things brighter for people who have got HIV because it puts people in a depressed state of mind where they isolate themselves. They feel they can’t go and do what they want to do; they feel they are quite limited in the things they can do”. Julius [person infected with HIV];

“The other times you can get it [HIV] in the press, is when an HIV person is facing prosecution for transmission. And often you may also see it is a side column saying: ‘Immigrant gives somebody HIV’; or man ‘purposely gives woman HIV’. Now obviously that doesn’t always help with stigma. So you see that HIV only features in the newspapers when somebody has given it [HIV] to somebody else”. Rita [information provider];

“HIV is something that is not put under consideration unless they already link it with something that already has stigma attached to it such as immigration. In newspapers, every time I hear about HIV, it’s like: ‘An immigrant has infected someone with HIV. This one with HIV has raped the other one’”. Claire [information provider].

HIV/AIDS-related information was also perceived to be stigmatising due to the unpleasant terminology and strong metaphors, including ‘victim’, ‘killer disease’, ‘deadly plague’, ‘HIV-positive’ and ‘germs’, that were frequently employed to refer to HIV/AIDS. This could result in unfounded fear about HIV/AIDS and PI/A HIV/AIDS, and thereby influence members of the community to stigmatise persons infected with HIV:

“... They say that it is a killer disease. That is it. You know! Killer disease! [interviewee’s emphasis] Can you associate with someone who has got a killer disease? [Respondent laughs] Can you eat with somebody who has got a killer disease? You can’t. Why should you come near, he has got a killer disease; you never know, maybe by touching him you will catch it. So they need to realise that ‘killer disease’ are strong words to use”. Hope [person infected with HIV];

“You see the media using terminology like ‘the HIV victim’ or ‘innocent victim’; you know the terminology used just puts blame onto the HIV-positive person. It’s the other one who gets it who is innocent, is the ‘poor them’; the one that transmitted the disease is the guilty one, the bad one. So we see in that way, the media has greatly influenced communities to stigmatise people with HIV/AIDS because of the terminology they use. There is also the case of using terms like: ‘Oh, it is a gay plague’. [...] They just say whatever they want to say, like last time they were saying: ‘Oh, a cure might be found for this deadly plague,’ something which brings fear to people”. Susan [information provider].

The analysis of data has also highlighted the wide spread negative reporting about HIV/AIDS in the media:

“You never hear information teaching about HIV or research findings about HIV. Actually it’s an ignored area. People still think HIV/AIDS is death. It is an ‘African thing’, it is a ‘Gay thing’; it is not for you and me. Supposedly ‘asylum seeker or gay rapes girl’; you know, kind of things like that, so it becomes a signifier of guilt. You know, the TV programmes have been sensational. [...] they’ve not challenged the stigma. So where HIV has featured in popular culture, it has not been necessarily beneficial. In the 1980s, HIV was associated with fear and guilt, and this has not been challenged today because it is still something that is attached to gay men, African people and young people”. Sarah [person affected by HIV].

To summarise: stigmatising information could be embarrassing and emotionally disturbing to PI/A HIV/AIDS. The analysis of data has revealed that people could engage in covert information seeking and hiding information as a result of the fear of being embarrassed and stigmatised. Respondents felt that stigmatising information could be counterproductive because it could hinder fruitful interaction with HIV/AIDS-related

information. In contrast, disseminating positive information about HIV/AIDS could potentially reduce HIV/AIDS-related stigma and prejudice, enhance interaction with HIV/AIDS-related information, and empower PI/A HIV/AIDS

7.3.6 Overly technical information

In the context of this study, ‘overly technical information’ refers to information that is incomprehensible to lay people, or cannot be understood without further help. The data indicated that HIV/AIDS-related information can be very hard to understand without help from medical practitioners, information providers and expert patients. The analysis of data has indicated that medical jargon and/or scientific terminology, such as ‘viral load’ and ‘CD4 count’, or high levels of English, were frequently employed in many HIV/AIDS-related information resources. Respondents complained that heavy scientific terms in biomedical information resources made reading biomedical information materials an extremely intimidating task:

“You know, if I talk about viral load or CD4 count, not everybody understands that. So if I said: ‘You’ve got an undetectable viral load, your risk of transmission is 1 in 100,000’, that doesn’t mean anything to anyone who doesn’t understand viral load and the CD4 count. The important thing is to have a balance between medical experts’ language and general people’s language”. Claire [information provider];

“The disease has had effects on me; I have lost sight in this eye, I have lost both my knees to it because my immune system thought the knees were a foreign object and it crushed them. I read articles, the doctors gave me articles, and I read about what was happening to my knees but they were very, very technical; I didn’t really understand them. It is absolutely too technical! Yes it is too technical”. Ben [person infected with HIV];

“I mean, when we access HIV information there is *Positive Nation*, and *Treatment Updates*. I have been finding information from journal such as the ‘American Scientist’ they have a column on ARVs and enzymes, so it can be over-scientific. So they need to present this in simple terms that the general public can understand, instead of using jargon in HIV research which could be more simplified”. Julius [person infected with HIV].

The analysis of data also indicated an urgent need for information resources that are written in simple laypersons' language:

“It goes back to what I was saying earlier. People need incredibly simple information. I mean, there is a reason why politicians use one-line [precise] information when they want to get a new policy across, or whatever. A single line of information, if it is accurate and it gives a lot of detail, can work. To be able to say HIV can affect anyone. If that piece of information could go across to people so that it is not stigmatised. If people can know that HIV can affect anybody and that getting it is not the end of the world”. Jack [information provider];

“The official jargon, oh no, it's not down to earth. You need to talk in layman's terms for everybody to understand. I mean, can you imagine going into a school and giving them all this government jargon and expect them to understand? And do you think if I went into a school and told them in a simple, easy way, even in their language, in their slang if need be, they wouldn't understand?” Jo [person infected with HIV].

To summarise: the respondents felt that technical jargon and scientific language in information resources could make HIV/AIDS-related information resources inappropriate and unhelpful. They reiterated the need for resource materials written at a level that the layperson can understand.

7.3.7 Misinformation

Misinformation, in the context of this study, refers to untrue, incorrect, over-dramatised, exaggerated or stereotypical information about HIV/AIDS. The analysis of data revealed that false HIV/AIDS-related information could be distressing, threatening and frustrating to PI/A HIV/AIDS:

“...when I was diagnosed they told me I couldn't have any children; that was 14 years ago, so why do positive people now get pregnant? And they said to me: ‘Unless you have £5000 to spend, we cannot do it for you. If you don't have money, go away.’ I can't understand why they did this to me”. Juliet [person infected with HIV];

“I thought that we have to be cremated. I thought we did. In the olden days that's what happened. You had to be cremated. In the olden days they thought that if we were buried we would contaminate the earth. When I told her [Name of friend infected with HIV] about that and she did not want to be cremated, she looked very disturbed. I said: ‘You know, don't take my word as gospel truth, come and ask at [Name of HIV support group].’ That turned out to be old information that I read a long time ago, but I never questioned it and took it as gospel truth”. Jane [person infected with HIV].

Misinformation, particularly myths about HIV transmission, can also be threatening:

“It was over dramatised how you can catch it. Before I had my THT course, I had thought my daughter could get it by using my toothbrush. I thought that you could get it like that. I thought if you used the same fork you could get it like that, I don’t know where it comes from, but misinformation is the worst. It sends you a bit crazy”. Jane [person infected with HIV];

“...especially at the beginning, I did not have a clue, neither me nor my mom really knew what it [HIV] meant. Because my dad found out really late and he was really ill. It was a hard time because all we had were the stereotypes of what HIV was in the 80s, that it was a death sentence”. Sarah [person affected by HIV];

“...it’s really, really hard to break cultural beliefs, or beliefs that people have held for so long. Like when the first cases of HIV came out; basically, the first cases were homosexuals, so people held onto that message that it’s just for homosexuals. And for some it is still how it is seen, because today [at the conference] it came across in a message that it’s for heterosexuals who are promiscuous, and other people held onto that. Up to this day people hold on to the message that, no, you can’t get it if you are not promiscuous, or if you are not gay or anything like that”. Mary [information provider].

Misinformation, including over-dramatised, exaggerated and stereotyped information, could be responsible for the excessive fear of persons infected with HIV/AIDS and aggravate HIV/AIDS-related stigmatising and discriminatory tendencies:

“People fear sharing cups, while others, when they touch somebody who is HIV-positive, they say: ‘Oh no.’” Peter [person affected by HIV];

“... you know , I had a friend, she was complaining. She went to her brother’s house, and she was HIV-positive, and they said: ‘Whatever she used, take them and bin them, we don’t want to transfer it to our children.’ So they had to bin all the bedding and everything she used, because they were scared that she will transmit HIV to them. That was terrible. Most of these people don’t know anything. And that makes them treat people with HIV badly”. Hope [person infected with HIV].

Respondents suggest that the distress and frustrations posed by misinformation could hinder effective interaction with HIV/AIDS-related information. Misinformation could also compromise the quality of life as people could possibly make decisions based on wrong information, thus making living with HIV very complicated. The effects of misinformation on HIV/AIDS-related information behaviour are discussed in detail in Chapter eight.

7.3.8 Summary

Section 7.3 presented evidence that the HIV/AIDS information world is full of information disconnects, ranging from lack of information, excessive information, information that ‘others’ HIV, stigmatising information, and overly technical information, to misinformation which makes interaction with HIV/AIDS-related information an extremely daunting task. The analysis has indicated that information ‘disconnects’ may not only make living with HIV/AIDS very difficult but also may jeopardised efforts to prevent and manage HIV/AIDS. The analysis also indicated that particular information sources were linked to particular information disconnects. For instance, popular culture was in most cases associated with stigmatising information; the Internet was associated with information misinformation and overload; books, and journals were blamed for old and over-technical information; while magazines and websites were blamed for portraying HIV as a disease for Africans, gay men and immigrants.

An overarching theme in Section 7.3, is that the ‘disconnects’ could hinder effective interaction with information, and make it difficult to address the information needs that arise from an HIV diagnosis. This finding is consistent with previous studies such as those of Johnson and Oliveira (1987), Carducci et al. (2011) and Helman (2001), who observed that people’s decision to interact with information could be influenced by the tone, clarity and perceived intention of the message. Chapter eight discusses in detail the relationship between information disconnects and information behaviour.

7.4. Conclusions

Chapter seven has provided insights into the nature of information resources within the HIV/AIDS-related information world of PI/A HIV/AIDS who participated in this research. The chapter also highlighted HIV/AIDS-related information ‘disconnects’ the respondents

experienced in the course of accessing and using HIV/AIDS-related information. The ‘disconnects’ identified, if un-abated, could compromise efforts to prevent and manage HIV/AIDS as will be discussed in Chapter eight. The study therefore suggests that interventions geared towards reducing the HIV/AIDS-related disconnects are urgently needed.

CHAPTER 8- THE ANATOMY OF HIV/AIDS-RELATED INFORMATION BEHAVIOUR

8.1. Introduction

Chapters five, six and seven revealed that a positive HIV diagnosis is a significant life-event because when HIV/AIDS occurs there is always a significant impact for individuals, families, communities and nations and could have a great impact on people's information behaviour (Stanton et al., 2007; Medley et al., 2009; Veinot and Harris, 2011).

Chapter five identified HIV/AIDS-related information behaviour such as seeking, sharing, avoiding and destroying information – also described as HIV/AIDS-related information coping processes (Lazarus, 1993). Chapter six identified a wide range of post-diagnosis reactions while Chapter seven explored the nature of the HIV information world including information, information resources and information 'disconnects'. Thus Chapters five, six and seven are the result of the analytical approach related to domain, taxonomic and componential analyses. These were aimed at identifying the components of a model of HIV/AIDS-related information behaviour, consisting of HIV/AIDS-related information behaviour, post-HIV diagnosis reactions, and key aspects of people's HIV/AIDS-related information world. The domains, taxonomies and components in chapters five, six and seven represented a fragmented account of the HIV/AIDS information context. This necessitated a further level of analysis in order to show the complex inter-relationships between domains and sub-domains.

The researcher therefore embarked on a higher order thematic analysis in sections 8.2-8.6 below in order to identify more complex relationships between, and within, the domains and sub-domains identified in Chapters five, six and seven. She also relates these to the body of existing literature in order to generate a holistic view of the HIV/AIDS-related information context. Thus, Chapter eight sets out to examine interactions between HIV/AIDS-related post-diagnosis reactions (reactions by PI/A HIV/AIDS and the wider community), the information world, and HIV/AIDS-related information behaviour, in order to generate rich and deeper insights about HIV/AIDS-related information behaviour. The intention in so doing is to generate a model of HIV/AIDS-related information

behaviour. This model consists of the determinants of information behaviour, resultant information behaviour, and overall effect on individual and community efforts to fight HIV/AIDS. The implications of the findings of this study for HIV-related information management practice, strategy and policy will be discussed in detail in Chapter nine.

8.2. The relationships between HIV/AIDS-related post-diagnosis reactions and information behaviour

Section 6.2 provided a detailed description of typical post-diagnosis reactions experienced by PI/A HIV/AIDS. These ranged from shame, guilt, devastation, hopelessness, worthlessness, fear and stress, fear of other people's reactions, fear of how the disease will progress, fear of isolation by family and friends, denial, shock, loss, grief, and loneliness; to worrying about infecting others and coming to terms with HIV. Section 8.2 of this chapter highlights ways in which the post-diagnosis reactions by PI/A HIV/AIDS influenced HIV/AIDS-related information behaviour. The aim in so doing is to generate in-depth knowledge about ways post-diagnosis reactions shape HIV/AIDS-related information behaviour. In turn, this knowledge can be used to inform the design of HIV/AIDS-related information interventions that are sensitive to the emotional needs of this group of information users. The implications of post-diagnosis reactions on HIV/AIDS-related information management practice, policy and strategy are discussed in Chapter nine.

Work on stress and coping such as Lazarus and Folkman (1984), Lazarus and Folkman (1986), Lazarus(1999), Lazarus (1991), Lazarus (1993), and work on stigma management such as Goffman's (1963) stigma management theory, provide a useful theoretical framework for interpreting the interview data generated in the context of people faced with a life-threatening and stigmatising health condition – HIV/AIDS.

The key components of the stress theory are: (a) an appraisal by an individual of the significance of a situation, and (b) coping; i.e., their attempt to manage associated demands on them. Stress may be experienced insofar as a situation perceived as significant to the individual has associated demands which 'tax or exceed available coping resources'(Lazarus and Folkman, 1986). Coping strategies may be problem-focused or emotion-focused. Lazarus (1991) elaborates nine negative emotions (i.e., anger, fear, shame, guilt, sadness, envy, jealousy, disgust and anxiety) and four positive emotions (i.e.,

happiness, relief, pride and love). Both emotion-focused and problem-focused coping strategies were observed in the current research. These entailed a range of information behaviours including hiding, avoiding, seeking and sharing information.

Emotion-focused and problem-focused reactions to both internal and external factors may affect information behaviour, including its components such as judgements of the relevance and usefulness of information. In this context, external factors will include the nature of the information with which the person comes into contact (either through searching or less actively) whereby information may be considered too technical, alarmist, highly inappropriate, or stigmatising as described in Section 7.3.

According to Lazarus and Folkman (1984), stress is viewed as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his/her well-being. Thus the judgement that a particular person-environment relationship is stressful hinges on cognitive appraisal. Lazarus and Folkman's (1984) definition of psychological stress helped to explain post-diagnosis HIV/AIDS-related psychological stress in relation to the different forms of information behaviour that PI/A HIV/AIDS adopted in the course of living with HIV. Therefore Lazarus and Folkman's (1984) Stress appraisal and coping theory, to a great extent, provided explanations for the information experiences and /or information behaviour within an HIV/AIDS-context.

Lazarus' (1993) definition of coping as on-going cognitive and behavioural efforts to manage (including to master, reduce or tolerate), specific internal and/or external demands and conflicts among them, was useful in generating understanding of the adaptive and/or non-adaptive cognitive and behavioural information-related strategies that people adopted so as to manage (reduce and/or tolerate) the debilitating effects of HIV/AIDS. The forms of information behaviour identified are not described as positive or negative although some behaviours are deemed more beneficial than others. This finding is consistent with Lazarus (1993), who observed that there is no universally good or bad coping process; although some might more often be better or worse than others.

This study revealed that, frequently, an HIV diagnosis was perceived to be challenging, harmful and threatening to the well-being of the person infected with HIV/AIDS or those with special relations with them.

The analysis of data suggested that a need to cope with the anticipated HIV/AIDS-related complications could motivate information seeking:

“... I wanted to find more information about what was going to happen, how long I was going to live, what the medications were going to do, whether I could go ahead with the career that I wanted to do, it was huge. ...But there are other worrying issues. I could die from a heart attack I could die from diabetes, I could die because my medications stopped working, but I am doing everything within my power from the information [...] I mean there is new information coming and the big thing for me that terrifies me absolutely is developing dementia sooner. I really don't want to be alive suffering from Alzheimers”. Job [person infected with HIV].

Thus, it is not surprising that information on general welfare and quality of life was a crucial resource for people faced with the life-threatening illness – HIV/AIDS. The value of accurate, reliable and up-to-date information for this group of information users cannot be over-emphasised. It was not uncommon for people to express a need for information that would provide them with guidelines and support to maintain a good quality of life. Consistent with this reasoning are findings from studies in the developed world such as Harris et al. (2010), Hogan and Palmer (2005a), Hogan and Palmer (2005b), Huber and Cruz (2000), Veinot (2010), and Zukoski et al. (2011), in which HIV/AIDS-related information was repeatedly described as a critical resource for people living with HIV/AIDS. Furthermore, studies in the developing world have also suggested that in the absence of a known cure or vaccine, information is crucial for preventing the spread of HIV. Some of the studies include Albright and Kawooya's (2007a) study on Libraries in the time of AIDS, Albright and Kawooya's (2007b) study on HIV/AIDS information seeking and healthcare communication in Sub-Saharan Africa, and Albright and Kawooya's (2005) study on the role of information in the reduction of HIV/AIDS prevalence in Uganda.

That notwithstanding, HIV/AIDS-related emotional distress and anxiety could undermine the value of information in the management and prevention of HIV/AIDS. For example, people experiencing negative emotions such as shock, or being upset or confused, may not engage effectively in information seeking. In some cases this could result in not seeking information:

“At that time, I was wild, I was upset, I didn't look for information. I had just thought to end it”. Julius [person infected with HIV].

In other cases it could result in hiding information:

“Well I didn’t disclose to my children for 12 months. And I lived in fear of them finding out.....
It was 12 months before June last year [2009]. I was so down at that stage, I went to bed crying, whether it was post-operative depression, whether it was just a build-up of everything, I don’t know. I couldn’t stop crying. I wouldn’t cry in front of anybody but as soon as I was on my own the tears could not stop flowing”. Jo [person infected with HIV];

while in other cases emotional distress could hinder interaction with information:

“at that point I did not have any information myself at all. I had had the infection that I had known about for 12 months; I didn’t learn anything about it. When asked if she knew about HIV before contracting it she just said that: ‘No I didn’t learn about it’...it [information] didn’t change my feelings at all. Talking to the counsellor did not change my feelings at all. I don’t know. I don’t think my head was taking in what he wanted me to take in. It wasn’t till I had my operation for cancer, that things started sinking in”. Jo [person infected with HIV].

Thus people’s emotional state can be a significant factor in shaping information behaviour, particularly for people faced with the life threatening illness HIV/AIDS:

“My ability to process information very much impacted on by my mental health and emotional well-being. If I am not feeling emotionally very well, then I can’t take information in, but that’s a choice. I really have a variety of emotional states. So there are times when I am more receptive to information, and other times when I am not. But I like the fact that I now live in a culture where if I wanted to go home, I could go onto the Internet and I could find information with the tap of a few keys on a keyboard. So I have the choice to access the information. Now the fact that I am choosing not to at the moment is just as valid as choosing to look...But you know, those are the kind of wider issues which contribute to me being able to access information. If I am feeling happy within myself then I can choose to access information....depending on your emotional state, you can’t sometimes take that information in. Sometimes it is too complicated; sometimes it is too technical and medical; while at other times you have just got a lot going on emotionally and you are just not receptive to that information. It has actually been to do with me and the state of mind I am in. So there is something about being able to access information when it suits you emotionally. I think you have to be emotionally ready to access information”. Job [person infected with HIV];

“... I started volunteering. I wasn’t ready to talk about my personal experience; I only wanted to listen to people. You know, he went first, and then I met the guy who was running it and I started coming in, and well I have been here ever since. You know, it has been a kind of process for me because I have grown up with [Name of HIV support group]. It has really been a place where I found information, I’ve gained experience, but I still don’t talk to my family about it because they’re all

over the country, and I don't talk to my friends about it largely because my Dad is doing well now. But then I guess I'm guilty of doing the same things as in those 'soaps' that marginalise HIV and render it invisible. You know [Name of HIV support group] has kind of grounded my experiences, my knowledge about HIV, and I do plan to talk to my friends and family more about it when I'm ready". Sarah [person affected by HIV].

In many instances the information received during emotional turmoil and distress was not useful because of the timing and the emotional state of information users:

"... they gave me information but it wasn't useful, because at the time of receiving a positive result, it is like receiving news that your beloved one is dead. You know when you have been well and then all of a sudden you are diagnosed, and people just calm you down and tell you that everything will be well. You ask yourself how? What are they talking about? ... but all the information I received at that time wasn't helpful". Monica [person infected with HIV].

The analysis also revealed that emotional distress could result in emotion-focused information seeking such as hysterical information seeking, or transferring whatever was read about HIV to themselves:

"I went to the library because I said I wanted to know more about all of this. I have got to know what is happening in my life. I went to the library and I just pressed on everything to do with HIV. Just pressed it and printed it. Press and print, I spent about £7-10 in the library, put everything in my bag. I went home and I started reading. And I said: 'Oh my God, I have got this, I have got that'". Jane [person infected with HIV].

This study suggests that, in the context of a life-threatening illness, that is, HIV/AIDS, people may be too anxious and distressed to even consider accessing and using any information, or sharing information about their status or understanding the information they are given. This finding points to a need for the design and implementation of HIV-related information interventions that consider the importance of the timing of information dissemination, and the emotional state of information users on effective interaction with information. An intimate appreciation of the post-diagnosis reactions by PI/A HIV/AIDS could potentially inform HIV/AIDS-related information management, strategy and policy. This could also inform the design and implementation of information-related interventions that are responsive to the needs of information users experiencing anxiety and emotional distress.

Emotional distress could hinder effective interaction with information, or stop people from seeking information. This finding is consistent with previous research such as Lazarus and Folkman (1984); Lazarus (1991); McCain (1992) ; Lazarus (1993); Fleishman (1994) ; Brashers et al. (2002b) where various social and psychological strategies that were employed to cope with illness-related stress were discussed. The findings point to a need to pay attention to people's emotional state in the design and implementation of HIV/AIDS-related information interventions in order to enhance the impact of information in the management and prevention of HIV/AIDS.

The findings have also indicated that, as people's appraisal of the threats, challenges and harm posed by HIV changed over time, so their emotional state changed from negative to positive (Lazarus and Folkman, 1987) as they came to terms with their condition and tried to change the troubled environment by engaging in seeking, and sharing information. Lazarus (1993) observed that the coping process was dependent on the context in which the disease occurred, and would change because people's appraisal of threats also changes over time. This study revealed that the respondents who were initially ashamed, angry and frightened, and hated anything to do with HIV, including HIV/AIDS information, reported having looked for information when their appraisal of HIV changed. Receiving information from, and interacting with, other people infected/affected helped them form a more positive appraisal of their condition (to come to terms with it) and thus reduced stress. This in turn resulted in seeking/sharing (as opposed to avoiding/concealing) information:

“I would personally read HIV/AIDS information anywhere, I have sat on trains and read HIV literature, such as Positive Nation, Treatment Updates, so it is not something that worries me. I know lot of people who would be extremely unhappy to do that. It is way along the process of people accepting the condition. You know I am 25 years old [living with HIV] so it's not a big thing to me. [Interviewer: Was it a big thing to you?] Oh yes. I mean for many, many years I wouldn't even say the word HIV; it was something I didn't want to talk about at all. Now, I can talk about it in public, it is a very big change over time. With the information I have at the moment I can refute it if someone says something incorrect about HIV. I can say to them no, no, this is wrong. I can explain to them, I can pass on that information to someone else. If I didn't have that information I would let that misconception go on, thus allowing people to believe the person who is wrong. So it enables me to talk with confidence about the disease that I have, and if you can speak with confidence about

something, it does reduce people's prejudice. And I found that very, very useful to be able to quote facts and figures and to be able to say to people: 'You know, this is how it is from my point of view'". Joel [person infected with HIV];

"I kind of shut it out for a while until he started getting better. Now my dad goes to one source and I go to another, and we come back and mix our information, and that often reveals a bigger picture. But it wasn't until I came to [Name of HIV support group] that I found some people who were positive, you know children of people who are also positive. I didn't share my experiences until then, but now I can. You know, it has been a long life experience". Sarah [person affected by HIV].

The following extracts from Jo [person infected with HIV] also illustrate the relationship between the emotional process and HIV/AIDS-related information behaviour. Making contact with other PI/A HIV/AIDS allowed her to have relief from having to hide her condition, and to come to terms with it in the sense of not caring about her status being known:

"Once I decided I don't give a damn what they think any more, but it sometimes comes back. That is the attitude that has come eventually. Especially at first you walk around thinking, who knows? Who doesn't know? Because you are so traumatised by yourself without realising that you're traumatised, you are passing those vibes over to other people. Because you look stressed and when they ask you why you are stressed you can't tell them. Then you start making excuses. You find yourself telling little white lies as to why you are stressed and why you look like that. You are looking for excuses for yourself. If you could get to a place like this [HIV support group] sooner rather than later, so that you can talk to other people about your experiences; once you meet people that are the same as you, that have gone through it, you feel relieved". Jo [person infected with HIV].

Having met and talked to others, Jo was able to engage in problem-focused information-related coping strategies such as seeking information, and reported that she found reading books about HIV beneficial:

"...Well, the book they gave me here [HIV support group] had a lot of information on HIV/AIDS and I learnt from it quite a lot. The *Positive* magazine is quite good. Because it tells you what people are doing with HIV, what they can achieve with HIV, that it is not the end of the road? You know it's no longer the end of the road. And you get other people's views. That why HIV sufferers put their stories in that book so that even if you have never spoken to anybody, that gives you a clue of what other people have gone through. So then you can be empathetic toward other people regardless of how they contracted the disease because everybody, everybody has that same feeling of desolation. It's just a total feeling of desolation. And from a mother's point of view, you should fight those desolations as hard as you can for your children". Jo [person infected with HIV].

Jo also felt able to share information in order to reduce the perceived threats, harm and challenges posed by HIV, and once her HIV status was made known to other family members, Jo felt happy to share information with them:

“When I was diagnosed, there was a piece of paper and I actually saved this paper [Respondent couldn’t find a copy]; there were potentially 144,000 people in [Name of city] alone that had not been diagnosed: not been in for treatment. The other people who had slept with them had been in and had been diagnosed. So that is a hell of a big number in [Name of city]. You know what I mean, it is a dangerous thing and I showed her [daughter] this paper and said: ‘I am not the only one’; I said: ‘Stop worrying, and there is treatment, on-going treatment. Stop worrying about my [emphasis] status. Stop worrying about your children’s status. Every one of them has come and asked for information and they don’t feel uneasy asking. I was happy with that because I thought they would withdraw but it made them closer to me, all except for one. She only comes in when her mom comes. She is a bit nervous to talk to me and she was the one that was quite close”.

The evidence presented so far has illustrated that people’s emotional state has a strong influence on how they interact with information. The study revealed that an HIV/AIDS diagnosis generated stress emotions for persons infected with HIV because it was appraised as threatening, taxing, challenging and harmful to their well-being. The data has demonstrated that, although information has long been understood as an important resource for people dealing with and comprehending the problems of living with a chronic illness like HIV (Huber and Gillaspay, 1998; Hogan and Palmer, 2005a; Veinot and Harris, 2011), HIV/AIDS-related stress emotions could hinder effective interaction with information and undermine the impact of information in the prevention and management of HIV/AIDS. HIV/AIDS-related information behaviour is motivated, to some extent, by an individual’s psycho-social reality which exists in tandem with biophysical complications and stigma. This finding is consistent with Huber’s (1998) observation that HIV is complicated by a myriad of factors outside the medical arena.

This study has also demonstrated that the emotions and coping patterns of PI/A HIV/AIDS changed dramatically over time depending on the circumstances they experienced. This finding confirms Lazarus’s (1993) observation that the coping process was dependent on the context in which the disease occurred and would change because people’s appraisal of threats also change over time. With respect to information behaviour, seeking and sharing information typically occurred when people’s appraisal of the threats, challenges and harm

posed by HIV changed over time, and/or when their emotional state changed from negative to positive (Lazarus and Folkman, 1987).

Information avoidance was the coping strategy most employed during emotional turmoil and in instances where people believed information may cause unpleasant emotions or diminish pleasant emotions, and/or needed to maintain hope and manage flawed information (Brashers, 2001; Case et al., 2005; Sairanen and Savolainen, 2010; Sweeny et al., 2010; Barbour et al., 2012). It can therefore be inferred that information-related problem-focused coping strategies, such as seeking and sharing information, are closely associated with changes in emotions from negative to more positive; while emotion-focused coping strategies, such as information avoidance, were mostly employed to reduce emotional distress.

These findings suggest that models of information seeking behaviour which emphasise rational library-based search processes such as those involved in scholarly and work-related information seeking like those of Kuhlthau (1993a), Wilson (1999), Ellis (1993) and Foster (2004), focus on information seeking contexts that are not as emotionally distressing as those of HIV/AIDS. In addition, the models emphasise information seeking and the benefits of acquiring information, and assume that individuals seek or pay attention to information. However, they do not consider instances when people may not opt to look for information (Case et al., 2005; Narayan et al., 2011). Therefore these models cannot effectively explain information behaviour within an HIV/AIDS context where a wide range of patterns of information behaviour, other than information seeking, occur.

Kuhlthau's (1993a) Information Search Process model is based on the premise that uncertainty is a cognitive state which causes affective symptoms of anxiety and lack of confidence in the information search process. Although the model is valuable in illustrating the confusion, frustration, anxiety and vagueness experienced by individuals searching about a specific topic or question, it makes no attempt to show how feelings such as emotional distress, shame, guilt and embarrassment may influence the search process, and also shape information behaviour.

This study has increased our understanding of the ways in which people's emotional status enhanced or hindered effective interaction with information. While Kuhlthau (1993a) posits that people experience emotions at the beginning of a search process and overcome

this towards the end of the search process, this study suggests that PI/A HIV/AIDS experience on-going positive and/or negative emotional processes which greatly influence their interaction with information. Thus information behaviour within the everyday context of a stigmatising, life-threatening and distressing condition may present different challenges, dilemmas and frustrations compared to a search focusing on one topic, question or project.

8.3. The relationship between social dimensions of HIV/AIDS (stigma and prejudice) and HIV/AIDS-related information behaviour

Section 8.2 illustrated how the respondents' emotional state could influence information behaviour. This section highlights the role of the social dimensions of HIV/AIDS in shaping HIV/AIDS-related information behaviour.

This study has shown that HIV/AIDS is a highly stigmatised illness, and people diagnosed with HIV/AIDS or those with close relations with them, often became victims of discrimination, prejudice, stigma and violence. Studies on stigma in the developed and developing world illustrated that despite improved testing services, effective treatment and legislation to protect people living with HIV from discrimination, HIV/AIDS-related stigma is still pervasive and plays a unique and disturbing role for the growing number of people living with HIV/AIDS (Alonzo and Reynolds, 1995; Lawless et al., 1996; Scott, 2001; Terrence Higgins Trust, 2001; Zhou, 2007; Anderson et al., 2008; Veinot, 2009; Zhou, 2009; Colbert et al., 2010b; Tiffany, 2010; Veinot, 2010; Veinot and Harris, 2011; Zukoski et al., 2011).

Stigma is defined as an attribute that is deeply discrediting and leaves the stigmatised person with a spoiled identity which must be managed in interaction with others (Goffman, 1963; Veinot, 2009; Colbert et al., 2010a; Tiffany, 2010). Section 6.2 described a range of apparently arbitrary negative reactions by others such as cruelty, intolerance, moral judgement and widespread hostility from family and friends, and various categories of health-care professionals, as well as the wider community with which PI/A HIV/AIDS interacted.

This sections sets out to describe the relationship between perceived and/or experienced harm and threats from other people and HIV/AIDS-related information behaviour, with a

view to generating knowledge that could inform the design of information interventions that are sensitive to the needs of this group of information users. The analysis of data showed that fear of other people's value judgements was a major obstacle to seeking and sharing HIV/AIDS-related information. In some cases the respondents faced the difficult decision of whether to, how to and to whom, to disclose their HIV status. This sometimes resulted in emotion-focused strategies such as concealing information:

"...I found it really difficult because I didn't talk to anybody other than my mum and dads about it really, not even my brothers and sisters. My mom, you know she had a similar experience she looked so shocked. I felt quite alone. I could not talk to my friends about it because even though I didn't know that much about it, I knew it was bad. Because I knew it was bad, I kind of thought I don't want people starting asking questions about how he got it, or start judging him and start judging us as a family. Like I said, I haven't talked to my sisters and brothers or anyone, which shows that I am affected by stigma and afraid that people will judge us as a family". Sarah [person affected by HIV];

"Well, I will arrange my house, clear away the HIV [magazines] .Well I wouldn't want him to know, but if he comes across it and says: 'Eh, what is this HIV?' I will tell him it is just a magazine I am reading. What is wrong with reading an HIV magazine?" Fiona [person infected with HIV].

In other cases, fear of social stigma resulted in information avoidance:

"I don't go on the Internet to read about HIV because when my son clicks the 'H' button he will see that I am reading about HIV". Belinda [person infected with HIV];

"I spent many years in isolation away from people with HIV and away from people who were talking about HIV.[...] For a long time, in my isolated state, there were times when I thought I just don't want to know. And I think that was an effective strategy for me because I didn't worry too much and worry is not good for HIV". Joel [person infected with HIV.]

Fear of stigmatising tendencies and moralistic judgments from family, friends and members of the wider community resulted in discomfort about being seen to have any association with HIV/AIDS, including resource materials, particularly for respondents who had kept their HIV status private. Thus most respondents resorted to seeking and using information under cover, also known as covert information seeking in the context of this study:

"In the Library, I saw a magazine; I picked it up and started reading it. But I had this feeling that I shouldn't have picked it up because people were observing what you are reading, what you are reading about? I took a magazine to work, but I wouldn't feel comfortable reading it where my

colleagues are [work colleague]. Regarding information in public areas such as libraries or on the Internet, issues regarding HIV, then it can be kind of stigmatising there; they are all looking at me. People are identifying you as a 'case person' [they are suspicious] so it is a bit difficult". Julius [person infected with HIV];

"When I was emotionally ready to access information it was very helpful. I mean, there were various magazines and books that I accessed. There was the AIDS Map: www.aidsmap.com; that's where I have got most of my information but they have a book called Living with HIV and I found that very useful. I also found very, very useful Positive Nation, it was very inclusive. It wasn't exclusively about HIV, there was sexual health, T.B., Hepatitis B, Hepatitis C. So it doesn't feel as threatening. Although I would like to confess sometimes feeling a little bit shy and anxious reading these in public". Job [person infected with HIV];

"I find it hard to read about HIV on a bus. It is not easy [participant laughs] that one; I can't read it on the bus, but in my room I will read it. But in the bus I can't read it. I cannot be on the bus or on the train and take an HIV book and read. That cannot happen". Fiona [person infected with HIV];

The analysis also revealed that perceived negative social costs of interaction with HIV/AIDS-related information such as stigma and discrimination, fear of being judged, and upsetting family members, could hinder interaction with information even among respondents who professed to have come to terms with HIV. For example Amos [person infected with HIV], who at one point said that he did not care if other people knew about his HIV status, reported that:

"...because I am watching television with you and I am HIV-positive and you are not, I don't want to try to pay attention to that because I think that you will say: 'Why are you listening to that?'" .Amos [person infected with HIV].

This could lead to a strategy of hiding information being employed:

"...I have the positive books laying around, and now I am saying they are laying around but when I know that my mom is coming around, I hide [emphasis] them away because my mom don't know. [Respondent laughs] Purely because my mom is old, 78 years old, my dad is 80 years old so if they knew it would freak them out altogether...I don't think it would be beneficial for them to know because they are not capable of doing much if I was in any danger. I didn't think it was necessary for me to involve them. My immediate family are involved, my children. I think this was a wise decision because if you broadcast it too wide it stretches. Elastic can only stretch so far before it snaps. I want to keep my knickers on [laughter]". Jo [person infected with HIV].

The analysis highlighted the effects of the social costs of interacting with HIV/AIDS-related information and pointed to a need for interventions that could provide information services within environments that could reduce the social costs of interacting with HIV-related information described above. The study has shown that the respondents' perception of the cost of engaging in information behaviours determined the pattern of information behaviour they employed in different contexts. For example, in situations perceived to attract abuse and discrimination, information avoidance and/or covert information seeking were employed. This finding confirms earlier studies on information behaviour in organisational contexts where researchers observed that an individual's perceptions regarding costs, such as loss of self-esteem associated with particular information seeking strategies, would impede information seeking (Baliga and Jaeger, 1984; Jablin, 1987; Johnson et al., 1995). Although these studies were conducted in formal organisational contexts, which are very different from that of the current study, their observations are relevant to the current study whose results have indicated that information behaviour in a stigmatising context, is dependent upon the perceived costs of engaging in such behaviour on one's self esteem.

On the other hand, stigma-free environments such as HIV support group premises, HIV clinics, and HIV conferences, not only facilitated information sharing among PI/A HIV/AIDS, but also facilitated information sharing beyond the confines of the HIV support groups by people who hitherto could not talk about HIV with anyone:

“I particularly like working with [HIV support group] because there are a variety of people and people that are affected by HIV and well as those that are infected; I think that is a very important issue for me as a HIV-positive person. I have my own stuff to deal with but I have got a whole network of family, friends and colleagues that are aware that I am HIV-positive. And that's new. That has been useful in talking to other people who have the experience of being HIV-positive. Because one of the big things I think was significant to me because, I didn't speak to another person knowingly who was HIV-positive for five years. And its only five years ago when I started being involved with [Name of support group] that I actually knowingly spoke to another person who was HIV-positive. And although their experiences are totally different, being able to speak to another person who has some comprehension of what it is like to be HIV-positive was very, very, very helpful. Actually speaking to another person, knowing that their experiences are different but also similar, is very helpful. And this is one of the main reasons why I do the work I do for [HIV support group] going into schools, because I think actually speaking to young people as a person with a story

to tell has much more impact on them than any amount of textbooks or leaflets". Joab [person infected with HIV].

The finding that HIV-friendly environments such as support centres and clinics could have beneficial effects such as stimulating information seeking and sharing, concurs with previous studies where it was observed that because of the stigma often associated with the disease, and the anticipated devastating physical consequences, HIV/AIDS activist organisations provide a unique environment for people living with HIV in which skills and resources are developed, experiences are shared, and useful interpersonally-provided information is accessed (Brashers et al., 2002b; Hogan and Palmer, 2005a; Veinot, 2009; Tiffany, 2010; Veinot and Harris, 2011; Zukoski et al., 2011).

The current study revealed that experienced and anticipated reactions such as stigma, prejudice, value judgements, physical and verbal abuse from members of the community, and fear of upsetting close family and friends, could hinder free interaction with HIV/AIDS-related information in public.

Although previous work on HIV/AIDS-related stigma has generated insights about the grievous effects of widespread hostility against people living with HIV/AIDS in medical and social contexts (such as impeding seeking medical attention, accessing HIV treatment and care, and testing for HIV on taking up employment, seeking help from family and friends, and starting new relationships), little attention has been paid to the effects of stigma and discrimination on information behaviour. The current study has extended the body of research on stigma by generating new insights into the effect of stigma on HIV/AIDS-related information behaviour; an area that has hitherto not been explored in-depth within Information Science research. It has unearthed forms of information behaviour such as covert information seeking, hiding, destroying and avoiding information, that could characterise the information behaviour of people faced with a not only life-threatening, but also a highly stigmatised, illness. Unlike people living with cancer, who may avoid information because of anxiety that is entirely related to the illness, as observed by Case et al. (2005), infection with HIV/AIDS results in a complex disease process complicated by other non-biomedical factors that compound living with HIV,

warrant adopting different forms of information behaviour, and render interaction with HIV/AIDS-related information complex. (Huber and Gillaspay, 1998).

This study has also revealed that, although people felt the need to seek and use HIV/AIDS-related information, issues of privacy, and confidentiality played a significant role in making information behaviour decisions. This finding is consistent with White's (2009) study on HIV/AIDS-related information behaviour among university students in three Caribbean countries where students were concerned about privacy of information sources and preferred to seek information in the privacy of their rooms. A similar finding was reported in Zhou's (2008) study on help-seeking in a context of AIDS stigma where persons infected with HIV employed secret keeping as a key strategy for them and their families to survive pervasive stigma.

Widespread fear of stigma from family, friends and the wider community, hindered the use of HIV-related information and HIV support group services. As discussed in Chapter five, support workers, also known as information providers in this study reported that some of their clients could not fully benefit from the services of the HIV support group because they hated being seen at the group's premises. Thus HIV support group workers adopted proactive outreach strategies such as sending resource materials through the post, meeting with clients in different locations outside the premises of the support group. This finding is consistent with Zhou's (2009) observations in a study of help seeking in the context of AIDS stigma in China, where multiple stigmas relating, for example, to immorality, contagiousness and lethality inhibited the most vulnerable people from accessing HIV/AIDS-related services such as HIV information, HIV testing and primary health-care.

Fear of other people's reactions (including being stigmatised and discriminated against), particularly for people who did not feel comfortable with visiting HIV support groups or clinics, was a barrier to accessing and using HIV/AIDS-related information. Although the HIV support group addressed this challenge by conducting community outreach sessions and home visits, only a small proportion of the population could be reached through those means. Fear of other people's reactions, coupled with sensational and incorrect information disseminated by the popular media, was not useful as far as the prevention and management of HIV/AIDS is concerned. Sensational, stigmatising and incorrect information resulted in two dimensions of fear: the fear of people who have HIV, and the fear of the rest of society about people with HIV and their own perceived risk of infection.

For persons infected with HIV, lack of information resulted in uncertainty, including acute fear of developing AIDS, guilt, fear of the unknown future and painful death, and fear of other people's reaction (mainly rejection). This finding confirms the concerns that portraying HIV/AIDS in a negative light, particularly by the media, could impede the rational assessment of the risks of HIV and jeopardise efforts to prevent and manage it (Pierret, 2000; Helman, 2001; Usdin, 2003; White, 2009).

In summary, stigmatising and discriminatory behaviour against PI/A HIV/AIDS could be emotionally depressing and hinder free interaction with HIV/AIDS-related information. Consequently, strategies such as covert information seeking, avoiding and hiding information could be employed by PI/A HIV/AIDS in order to safeguard themselves and their families against stigma and social discrimination (Lazarus and Folkman, 1984; Lazarus, 1993; Case et al., 2005; Lieber et al., 2006; Liu and Choi, 2006; Zhou, 2009). Thus, as well as affecting the mental and physical well-being of PI/A HIV/AIDS, non-biomedical complications could dramatically impact HIV/AIDS related coping strategies and ultimately undermine efforts to access and use HIV/AIDS-related services including information. This study has generated in-depth understanding of the effects of stigma, prejudice, and discrimination on HIV/AIDS-related information behaviour. This could potentially inform HIV information services design and management, and lead to information services that are responsive to the psycho-social needs of persons infected with HIV/AIDS. The study suggests that HIV/AIDS-related interventions should not only emphasise the dissemination of information as such, but should also endeavour to address issues relating to potential stigma, prejudice and physical and verbal abuse to ensure optimal access to, and utilisation of, information services, as will be discussed Chapter nine.

8.4. The relationship between information disconnects and information behaviour

Chapter seven highlighted significant problems with HIV/AIDS-related information resources, also described as 'HIV-related information disconnects' in Section 7.3. HIV-related information could not only be alarming, worrying and upsetting, excessive, or portraying HIV as a disease of 'others', but it was also sometimes perceived to be moralistic, sensational, stigmatising, overly-technical, incorrect and inadequate. Section

7.3 described frustrations, dilemmas and challenges the respondents experienced with HIV/AIDS-related information. The following sections focus on illustrating the relationship between information disconnects and HIV/AIDS-related information behaviour.

One ‘disconnect’ regarding the nature of HIV-related information is overload. As described in sub-section 7.3.3, respondents complained about feeling overwhelmed by the large amounts of HIV/AIDS related information available, some of which could also be inaccurate and unreliable. This study indicated that frustration with excessive information could influence information behaviour in different ways. In some cases it could result in avoiding and/or destroying information:

“I don’t get them from random websites because there is so much information; there is a weekly email that goes out with information and, as somebody with HIV that is just too much information. So I now don’t look at that information, I delete it off my email”. Job [person infected with HIV];

“...information is too much. It can be too much. Well, that is why you find that sometimes when I go to [Name of support group] meetings, I just listen; the information goes in through one ear and out through the other. Sometimes I don’t think what they are saying is important to me. Sometimes I am also ignorant. Someone can tell me something about stuff, because I may not think it is important at that time, I tend to ignore it. I don’t pay attention and maybe it is important. I just ignore it, but maybe it is important to me?” Fiona [person infected with HIV].

Information disconnects could in some cases result in emotional distress, and lead people into shifting from one type of coping strategy to another. The following interviewee, for example, having engaged in a problem-focused strategy of information seeking to inform himself about HIV/AIDS, encountered contradictory and worrying information, and consequently experienced anxiety and distress. The effect of this was that he reverted to an emotion-focused strategy, which led to the avoidance of this information channel:

“To talk about how I process new information about my HIV status... the fact that research is showing that HIV, or the medication, is increasing the ageing process; that is emotionally very hard. There are physical things going wrong with me that I can discuss with my mom who is 64, and she is having similar health problems, when I am 38. ...Research is indicating that, although I am 38 years old, they think my body is probably the age of a 58 year-old in terms of the ageing process. So getting more information about that side of things is becoming very important. One thing that is

significant to highlight is that I stopped accessing information from the Internet, from the websites I was accessing information from, because information was being made public too early in the research. Some pieces of research were saying one thing, and others saying something else, and I would get upset, very panicky and distressed by information overload. I don't ask other people that are HIV-positive any more. I have gone back to relying on my doctors...that suits me better than me finding information myself because I emotionally panic and get distressed by new information. ...there is just so much, it is too overwhelming". Job [person infected with HIV].

A key finding in this section is that persons infected with HIV had to contend with overwhelming amounts of information to keep up with, and stay current on, issues important to their health and general welfare. Excessive information resulted in emotion-focused information behaviour such as ignoring, hiding, avoiding and destroying information, as described above. Although emotion-focused information behaviour would be beneficial in the short term (for instance, by safeguarding against discrimination, desertion and other forms of abuse, or maintaining the dignity of the person or protecting members of the infected person's family from distress), given the magnitude of contextual demands such as the need to know about medications, relationships and dating, employment, death and dying, disclosure, and the disease itself (as discussed in Chapter five Section 5.3), emotion-focused coping strategies such as avoiding, ignoring, and destroying information, would be detrimental in the long run because people could miss important information. This finding confirms Lazarus' (1993) observation that denial, or wishful thinking, could have negative consequences when they stop people from trying more productive options. While previous studies such as Huber and Cruz (2000), Hogan and Palmer (2005b), Hogan and Palmer (2005a), found that HIV/AIDS-related information is complex, multidisciplinary, voluminous and outdated, they did not attempt to illustrate how these disconnects could influence HIV/AIDS-related information behaviour. The current study has, however, demonstrated that excessive information could be overwhelming and confusing, which could ultimately hinder efforts to access and use HIV-related information. Information overload hindered respondents' efforts to engage with, and effectively benefit from, HIV/AIDS-related information. This finding is consistent with the study by Brashers et al. (2002a), who observed that individuals under-utilise or do not utilise information if they find the information confusing, contradictory or overwhelming.

The analysis of data also revealed that, in addition to being overwhelmed by excessive information, people could experience lack of HIV-related information. Persons affected by HIV, especially children and parents of persons infected with HIV, expressed frustration with lack of the information they needed to enable them to deal with their emotional stress and to support their loved ones. A similar observation was made by Lambert et al.'s (2009) in-depth explorations of information seeking behaviour among individuals with cancer, in which users of cancer-related information expressed frustration about their inability to find clear information about treatment options. This section describes the relationship between lack of correct, reliable and up-to-date HIV/AIDS-related information (as described in Section 7.3.2) and HIV/AIDS-related information behaviour. The analysis showed that lack of information could influence HIV/AIDS-related information behaviour, particularly information seeking, among people faced with a life-threatening illness – HIV/AIDS:

“...first of all my sister was diagnosed with HIV and she was 23 years old. Now I did not know anything about HIV. I did think you could get it from a cup and these other things, I did think that. But I educated myself in order to support my sister. [Interviewer: How did you educate yourself?] Oh books, library, Internet, that was the only help for me to support my sister”. Annette [person affected by HIV];

“... especially at the beginning I did not have a clue, neither me nor my mom really knew what it [HIV] meant. Because my dad found out really late and he was really ill. It was a hard time because all we had were the stereotypes of what HIV was in the 80s, that it was a death sentence. We found he was in hospital, he was in a wheel-chair, he could not walk, it was really a big shock for all of us. And so I thought I need to find out about it [HIV]”. Sarah [person affected by HIV].

To summarise: lack of HIV-related information could motivate information seeking for purposes of responding to complex information needs that may result from an HIV diagnosis. This reasoning is consistent with previous work such as that of Barbour et al. (2011), Case et al. (2005), and Kuhlthau (1993a), where it was observed that the need to reduce uncertainty could motivate information seeking. Despite the potential of lack of information to stimulate information seeking, particularly for people dealing with a chronic illness such as HIV, lack of easily accessible and readily available information about HIV could frustrate the success of such information seeking. Without the requisite information, PI/A HIV/AIDS cannot readily find answers to day-to-day life issues. The concerns raised by persons infected with HIV suggest that information is a vital component as far as living

with HIV is concerned (Huber and Cruz, 2000; Hogan and Palmer, 2005a; Hogan and Palmer, 2005b; Harris et al., 2010; Tiffany, 2010; Zukoski et al., 2011). Hence the availability of biomedical, psycho-social and practical information could potentially improve the quality of lives of PI/A HIV/AIDS.

Although studies such as those by Siegel and Raveis (1997), Harris et al. (2010), Veinot (2010), Veinot and Harris (2011), and Huber and Cruz (2000), which discussed lack of readily available HIV-related information as a major challenge to PI/A HIV/AIDS, increase our understanding of the effect of a lack of HIV/ AIDS-related information on the lives of people within rural contexts, they could create an impression that HIV/AIDS-related information is readily available for PI/A HIV/AIDS who live in urban areas. However, the current study (whose respondents were urban dwellers) contributes to the existing body of knowledge by suggesting that lack of easy access to reliable and up-to-date HIV/AIDS-related information could be a major barrier to healthy living for urban dwellers as well. Hogan and Palmer's (2005a) study on information preferences and practices among people living with AIDS, which suggested that most HIV information is grey literature where publishing is not the primary activity, supports the reasoning that HIV/AIDS-related information is not readily available. They argued that access to HIV-related information could be difficult given its limited dissemination and integration into the usual streams of health information. This study suggests that inability to access HIV/AIDS-related information could disadvantage individuals and organisations that would benefit from it.

A lack of awareness of HIV/AIDS could delay HIV diagnosis (Zhou, 2009), leave people unprepared for an HIV-positive result, leave family members unprepared for the challenges of taking care of the ailing family member, and medical professionals unprepared to provide professional and compassionate medical care to HIV patients, all to the detriment of the quality of life of persons infected with HIV. Lack of knowledge about HIV/AIDS has been reported as the main cause of intolerance and stigmatisation towards persons infected with HIV and their close family members, as well as of indifference to prevention messages (Huber and Gillaspay, 1998; Usdin, 2003; Veinot, 2009; House of Lords Select Committee on HIV/AIDS in the United Kingdom, 2011; Zukoski et al., 2011). Such tendencies could undermine efforts to prevent and manage HIV/AIDS. The findings of this study point to a need for interventions that could promote easy access to

accurate and reliable HIV/AIDS-related information that not only creates awareness but also generates deeper understanding of the realities of HIV/AIDS. This knowledge could empower PI/A HIV/AIDS, and reduce discriminatory and stigmatising tendencies from the wider community.

Another alarming disconnect associated with HIV/AIDS-related information is the tendency for information in the media and popular culture to be stigmatising. The analysis also revealed that sensational and exaggerated information, as well as information that ‘others’ HIV, could cause emotional distress and impair cognitive information processing, hindering effective interaction with information and perpetuate HIV/AIDS-related stigma:

“The images of people with HIV in the early days before I was HIV-positive, they are all dying of AIDS, they are all skeletons, had cancers on their faces and that kind of stuff...That does still happen and I have to emotionally come to terms that that might happen to me. The possibility that the drugs could stop working, or possibly the drugs I take, the side-effects could be that my liver fails, my kidney fails, or I develop diabetes or I have a heart attack, that is a fact of my existence. That is a hard fact that that could happen but as an individual. I have got choices to make and sometimes I choose not to access any information”. Belinda [person infected with HIV];

“One film I didn’t like, which a lot of people know, is *Philadelphia*, I didn’t like that film at all because for me there were lots of stereotypes of HIV and gay men in there that I didn’t feel comfortable with, and they got in the way of information for me really. I said this is really ‘enough’ and ridiculous. I just said that I can’t be dealing with seeing that kind of stereotype of a gay man and HIV”. Job [person infected with HIV];

“You can never hear of information teaching about HIV or research findings about HIV. Actually it’s an ignored area. People still think HIV/AIDS means death. It is an ‘African thing’, it is a ‘Gay thing’; it is not for you and me. Supposedly ‘asylum seeker or gay rapes girl’, you know kind of things like that, so it becomes a signifier of guilt. You know, the TV programmes have been sensational. They’ve given visibility but they’ve not challenged the stigma. So where HIV has featured in popular culture, it has not been necessarily beneficial”. Sarah [person affected by HIV];

“...You know there was a lot of unpleasant media coverage in the tabloid press which is the kind of grubbier papers like the Sun, Star and the Mirror. And today in that kind of lower class, lower intellectual level papers, there were a lot of ignorant ideas. The information is quite biased so you have to put a filter in it. There are specific sexual health advertisements targeted at risk groups like men having sex with men. The reality is that there are some higher risk groups, and I think it is dangerous not to acknowledge that. This perpetuates the kind of prejudice and stigma. You know, I

think the media in this country is totally irresponsible, they sensationalise stories”. James [information provider].

Stigmatising information could make interaction with HIV-related information embarrassing. This was reported to be a major hindrance to attempts geared towards dissemination and /or sharing of HIV/AIDS-related information and lead to information avoidance:

“... we did an information stall at the [Name of university] in the student union building and we had leaflets and that kind of stuff and what astonished me was people were coming by, seeing what the banner was, and they were avoiding us. They were skirting around and not wanting to come and speak to us. And I was just like, what is that all about? You know! What are you frightened of? You know, do you think for a second you can become positive. If you touch a book that talks about HIV you gonna get HIV? Are you just embarrassed?” James [information provider].

8.5. The relationship between information connects and information behaviour

On the other hand, non-judgemental information was perceived to be useful and was reported to facilitate information behaviour such as information sharing:

“...It is the passing on information to people with different capabilities, different ages, not being too technical with the information that I am giving, using the right language, so they understand, not assuming. Like for example I have been in sessions where we said that we are heterosexual and they have asked, what do you mean heterosexual? Not making those kinds of assumptions, no I don't, I say people having sex with other people. I say a boy having sex with a girl. You know girl having sex with a boy, speaking their language, and if they use phrases, I use similar phrases; [...]it is important to use that language, reassure them, don't attack them and don't be moralistic”. Jack [information provider];

“Because I knew that was the only time in the whole of that school year that they were going to have the opportunity to hear my story, hear the stories from my colleagues, speak to another person who is HIV-positive, ask any questions, I mean the information we give is very, very important. It is not just about sexual health, it is about mental health well-being, what it means to be a good citizen and a good human being, about accessing health-care provision for them as young people, and letting them know the risks and dangers of HIV, and sexuality, but not adding to the stigma and fear, not wanting them to go away from that session frightened, never to have sex again, because when that kind of situation happens, that's when you need to worry because if they are anxious and worried about sex,

they are not gonna access further information and they are more likely to get themselves into difficult situations”. James [information provider].

An information connect could occur when people received information that clarified fears about future career prospects. Such information was reported to facilitate information seeking:

“I had a problem when I started my catering course I was thinking what if I cut myself? What if I have got a cold and then I sneeze; this food is going to the restaurant and people will be eating it, what will happen. So to ease my worries I went to the hospital. There are health advisors, they are well-informed and they know all the new information coming up about HIV. The person I asked talked to me and said it should not affect you because HIV is a very weak virus that can be killed by soap or even alcohol. It is not strong if it is not in your blood. So that was one problem solved. And then she told me that, if you have got a cold or whatever and you cough, it is not enough to infect anybody. Just like saliva you need so much of it to infect people. So she had information for me about; that she took it out for me and I went and read it. It was so calming so soothing. Since then I have done my course, I have never looked back. I am planning that may be one day I will have my own restaurant”. Monica [person infected with HIV].

An information connect could also occur when people received correct information about aspects of their general welfare; for example, ways of avoiding further HIV transmission, and treatment regimes. Although such information was not readily available, it was valuable when received. For example, Sam and Jane [persons infected with HIV] respectively reported that:

“Oh yes, the information that I think was most useful to me over the years was information about treatment, that’s always very important. Information about transmission is also very important for people to know how the virus is transmitted so they do not go about infecting others. As a positive person, that has always been my fear – passing the virus onto someone else. So information about that, and I did not get that information until it was very, very late. For a number of years we didn’t know how difficult it is to pass the virus on. So it is that sort of thing that had an impact on me and getting that sort of information was life changing”.

“...the THT people know what they are talking about. When I went for the THT course, they taught me everything to do with what medications are working in the body, why it is so important to take them at certain times, because you need to know why it is important to leave 10-12 hours between these pills. They teach you what the pill does. Like what it does in two hours, five hours, and why it is so important that when that pill stops working then you start another one to keep a level of this pill in your body. That is very good information because you need to know that before you start taking

pills, because it is for the rest of your life. The course changed my life. You know, when you are diagnosed with HIV, you think you going to have no life, you're gonna be by yourself, no one is gonna want you, you are not worthy, you think all these things. You see you are finished now. No man will love you anymore; you can't get love, nobody, and nothing. You think that is what life is gonna be like, be by yourself for ever, like I have got leprosy. That is what I thought to myself but the THT course changed my life". Jane [person infected with HIV].

The study has also shown that accurate information could not only restore confidence among PI/A HIV/AIDS but also could have a multiplier effect, including facilitating information sharing for purposes of clarifying misconceptions about HIV/AIDS and reducing HIV/AIDS-related prejudice:

"As far as my social life is concerned, with the information I have at the moment I can refute it if someone says something incorrect about HIV; I can say to them no, no this is wrong. I can explain to them, I can pass on that information to someone else. If I didn't have that information I would let that misconception go on, allowing people to believe the person who is wrong. So it enables me to talk with confidence about the disease that I have, and if you can speak with confidence about something, it does reduce people's prejudice. I found that very, very useful to be able to quote facts and figures and to be able to say to people: 'You know, this is how it is from my point of view and I am living with HIV'". Job [person infected with HIV].

To summarise: the manner in which information resources are presented greatly influences people's interaction with information. Thus it is not surprising that moralistic, stigmatising, sexist, racist and incriminating overtones (as discussed in Section 7.3.5) were perceived to hinder effective interaction with HIV/AIDS-related information. However, simple and non-judgemental styles could potentially enhance people's interaction with information. This finding is consistent with previous studies such as that of Johnson and Meischke (1993) on cancer related information-seeking relating to magazines, Johnson et al.'s (1995) study of information-seeking focusing on a technical organisation, which observed that perceiving a medium as having motives other than the mere provision of information weighs heavily on evaluation and exposure decisions. This study suggests that future HIV/AIDS-related information interventions should specifically endeavour to address HIV/AIDS-related information disconnects as a way to enhance the role of information in the fight against HIV/AIDS.

Unlike Hogan and Palmer's (2005) study of information preferences and practices among people living with HIV/AIDS, which only reported that the study participants expressed

concern that most of the information did not apply to them, this study has extended existing research on information behaviour to explain why HIV/AIDS-related information was perceived to be irrelevant. For example, information with incriminating, racial and sexual overtones was perceived to be irrelevant. This not only made interaction with that kind of information difficult, but made its dissemination complex, especially where people did not want any association with HIV/AIDS-related information because they felt it was not meant for them.

8.6. The relationship between information needs and information behaviour

Being diagnosed with HIV generated a wide range of information needs as described in Section 5.3 which stimulated information seeking. The analysis revealed a strong relationship between HIV/AIDS-related information needs and the corresponding information behaviour. In some cases, seeking information was motivated by the need to learn about health complications that arose from the HIV infection. For example, Monica and Joel [persons infected with HIV] respectively reported that:

“I also felt I was ageing too quickly. I sometimes felt so dry. I needed to know the lotion I could use on my skin. But if you are shy you cannot ask. With positive living and my confidence I can now go to the pharmacist or to my GP and say: ‘I am living with HIV; I really have a dry skin, what can I use?’ And then learn what I need to buy. Just like a normal person, you go to a chemist and say: ‘I have a dry sensitive skin or I have got a dry oily skin’. But most of us with HIV get a dry scaly skin and we need more oil. I am not bothered anymore because I am living a positive life. I am not doing it for anybody; I am doing it for myself”.

“I was so ill. This forced me into a situation where I had contact with people and it changed my life. Because I was able to speak to people who were positive, of course not with a life exactly like mine but with similar circumstances. It opened up a huge amount of information. It did two things: it opened up my willingness to ask questions, hum, it is really important if you are willing to ask questions, so I opened up and asked questions; I was able to talk to people I had never met before. I was able to talk to them. It increased my willingness to get information and find a way to get that information as well”.

The need to prevent HIV transmission was another major motivation for seeking HIV/AIDS-related information:

“The only information I sought was more about safe sex, how not to pass it on. When it came to my health I left it to the doctors who told me what to do and when to show up”. Ben [person infected with HIV].

The respondents also sought information in order to find out where to access emotional support and to learn about medications and their side-effects, as well as the effect of the HIV diagnosis on their career prospects. For example, Jane and Job [persons infected with HIV] respectively reported that:

“I needed a person I could talk to on a day-to-day basis; information about life after the death sentence so to speak. When you have just been diagnosed your world falls apart. And sometimes you go over the top. Yeah, you do things you wouldn’t normally do; I think more information on medication, more information on where to access someone to be able to talk one-to-one to. I had to go on the Internet; I had to find out more information”.

“...for me the most important information that I needed on that day, was about medication I was going to be taking, what side-effect the medication was gonna have on me, and also where to access emotional support from. And because I kind of discovered I was HIV-positive, um in a situation when it was a real shock. The actual formal test for HIV came as a real shock to me that I was HIV-positive. What was important to find out was information directly affecting me in ways that were private. That is why I sought out information from medical people first, from social workers, and the occupational health person, and it was my information. I had just completed a formal qualification to be a psychiatric nurse so for me it was very, very important to find out if being HIV-positive would stop me from doing the job I had been training for three years to do. So that was another really important piece of information that I needed to know. So it was very specific to my situation. I had to find out the procedures which I had to go through to let the right people know about my HIV status. Also the side-effects from my medication has been the main area where I have needed new information, and as I carry on living and surviving, new information is coming up about the long-term effect of the HIV virus or HIV medication, and that is a complex area really”.

In other instances information behaviour was stimulated by the need to seek and share information with close family members and colleagues:

“I have learnt much from [name of person] and I needed to learn more because other people looked to me for answers”. Ben [person infected with HIV];

“... there is a new pill that suppresses the progression of HIV. It is a trial and I don’t know if it is in the US, so he sent me the link and I am going to pass it on to people here [Name of HIV support group] that is the most recent. They found out that if you take medication and you don’t have any other STI [Sexually transmitted infections] the risk of transmission through sex is quite minimal. He was the one who first told me about that and then I went and read about it, and I came back and told him more information and we wrote about it in the newsletter here [Name of HIV support group]. You know, we have seen it come up again and again in different publications. So it is now in *Positive Nation* and they find new things we can follow a story on, and we do that quite a lot”. Sarah [Person affected by HIV].

From the information needs noted by respondents, such as the need to learn about the routes of transmission of HIV, treatment options, starting relationships, sharing information with colleagues, and disclosure (as discussed in Section 5.3), it appears that information is a vital resource in the lives of PI/A HIV/AIDS. This finding is consistent with previous studies which suggested that PI/A HIV/AIDS experienced information needs that ranged from drugs, wellness, financial information, social activities, HIV/AIDS disclosure, death and dying, and religious/spiritual topics; to HIV antibody testing, sexual transmission, non-sexual transmission, ways in which HIV is not spread, disease symptoms and processes, condoms and other protective barriers, safer sex behaviours, facts about HIV/AIDS, and statistical information about the HIV epidemic (Kalichman and Belcher 1997; Ko et al., 1997; Huber and Cruz, 2000; Zukoski et al., 2011).

Although previous studies of HIV information needs and information seeking practices among people living with HIV, such as those reported by Case et al.,(2005), Hogan and Palmer (2005a), Hogan and Palmer (2005b),White(2009), Veinot and Harris (2011), Zukoski et al. (2011), contribute to our understanding of HIV-related information needs, and of the most frequent sources and channels used by persons living with HIV, they do not provide a strong theoretical explanation as to why, unlike other groups, users in this group exhibited different forms of information behaviour including covert and hysterical information seeking, avoiding, hiding and destroying information.

Furthermore, HIV/AIDS-related information needs studies based on quantitative survey methods, such as those by Chou et al. (2004), Hogan and Palmer(2005a), Hogan and Palmer(2005b), cannot generate rich insights into HIV/AIDS everyday-life experiences, including ways in which HIV/AIDS related information connects and disconnects shape HIV/AIDS-related information behaviour. This ethnographic study addressed this gap by

generating an intimate appreciation of HIV/AIDS-related information behaviours including the dilemmas, frustrations, connects and disconnects from the point of view of PI/A HIV/AIDS. Rather than focusing on when and how people have accessed which information sources, this study has unearthed the complex information behaviour within the HIV-related information context. It has laboured to provide theoretical explanations for the different forms of information behaviour that were employed by this group of information users, with a view to providing a basis for evidence-based HIV/AIDS-related information service and product design and provision.

The above discussion justifies the need to develop a model to illustrate the complexities inherent in HIV/AIDS-related information behaviour that have hitherto not been accounted by the existing models as discussed in Section 2.2 .

8.7. Background and narrative of the model of HIV/AIDS-related information behaviour

Thematic analysis in Sections 8.2 - 8.5 entailed identification of relationships between the domains and sub-domains previously described in Chapters five, six, and seven, enabling examination of how the domains and sub-domains interact, in order to build a theoretical model of HIV/AIDS-related information behaviour. The analysis revealed that a positive HIV/AIDS diagnosis may be followed by a variety of reactions, needs, associated information needs and information behaviours, interactions with a range of different types of information sources, and related outcomes. These factors may interact to affect one another in complex ways, which may differ according to the particular circumstances of the person affected, the person's own reaction to the diagnosis, attitudes of other people towards him/her, and the nature of information resources with which s/he comes into contact. Thus Chapters five, six, seven and eight generated insights into information behaviour in the face of a diagnosis of a virus for which there is currently no vaccine or cure, for which conventional treatments may have unpleasant and very toxic side-effects, with prospects of a life of potential uncertainty, exclusion, stigma, discrimination and abuse from family, colleagues and the community, and a complex information world with information resources full of 'disconnects'. The analysis of data has shown that the reality for a person infected with HIV is living daily not only with the medical uncertainties posed by HIV/AIDS, but also with the stigma, discrimination and prejudice caused by fear from

the rest of society about people with HIV, and their own perceived risk of infection. The current study has led to a proposed model which not only describes the forms of information behaviour people could adopt, and explains why such behaviours could be adopted, but also considers how they could potentially be used to predict HIV/AIDS-related information behaviour. However, the predictive ability of this model would require testing in a large-scale longitudinal quantitative study.

The proposed model also takes into account the complexities, subtleties, dilemmas and challenges associated with accessing and using information in the context of a life-threatening and stigmatising illness – HIV/AIDS. The aim in so doing is to generate understanding of the nuanced ways in which interactions with information may be enhanced or impeded, in order to inform the design and implementation of information related interventions that are sensitive to the needs of information users in life-threatening and stigmatising contexts.

The model presented here pays close attention to the everyday information behaviour of PI/A HIV/AIDS. It also explores the relationships between psycho-social (internal) factors, including feelings and emotions (affective aspects), thoughts and beliefs (cognitive aspects), external factors such as the social environment (other people's reactions), and the HIV/AIDS-related information world (including the nature of information resources), in order to generate insights into forms of HIV/AIDS-related information behaviour. Thus the model emerged from, and is informed by, data analysis of 'lived information experiences' of PI/A HIV/AIDS, including HIV/AIDS-related information behaviour and the drivers of this behaviour. The model attempts to describe patterns of HIV/AIDS-related information behaviour and explains why such patterns could develop in the HIV/AIDS-related information context.

The specific aim is to move beyond relatively reductionist and simplistic representations of information behaviour by developing a model that addresses the finer details of the complexities of human information behaviour, particularly life-threatening and stigmatising health-related information interactions. This could potentially illuminate ways in which information services could be responsive to the needs of PI/A HIV/AIDS, and provide a basis for proposing recommendations for information management in health contexts. Thus, in addition to paying attention to how and when people relate to information, the model highlights challenges and dilemmas experienced by people faced

by the life-threatening and stigmatising illness: HIV/AIDS, in order to generate rich insights about the complexities and subtleties within the HIV information world in order to inform future HIV information-related interventions. Such a model is presented diagrammatically in Figure 6 below.

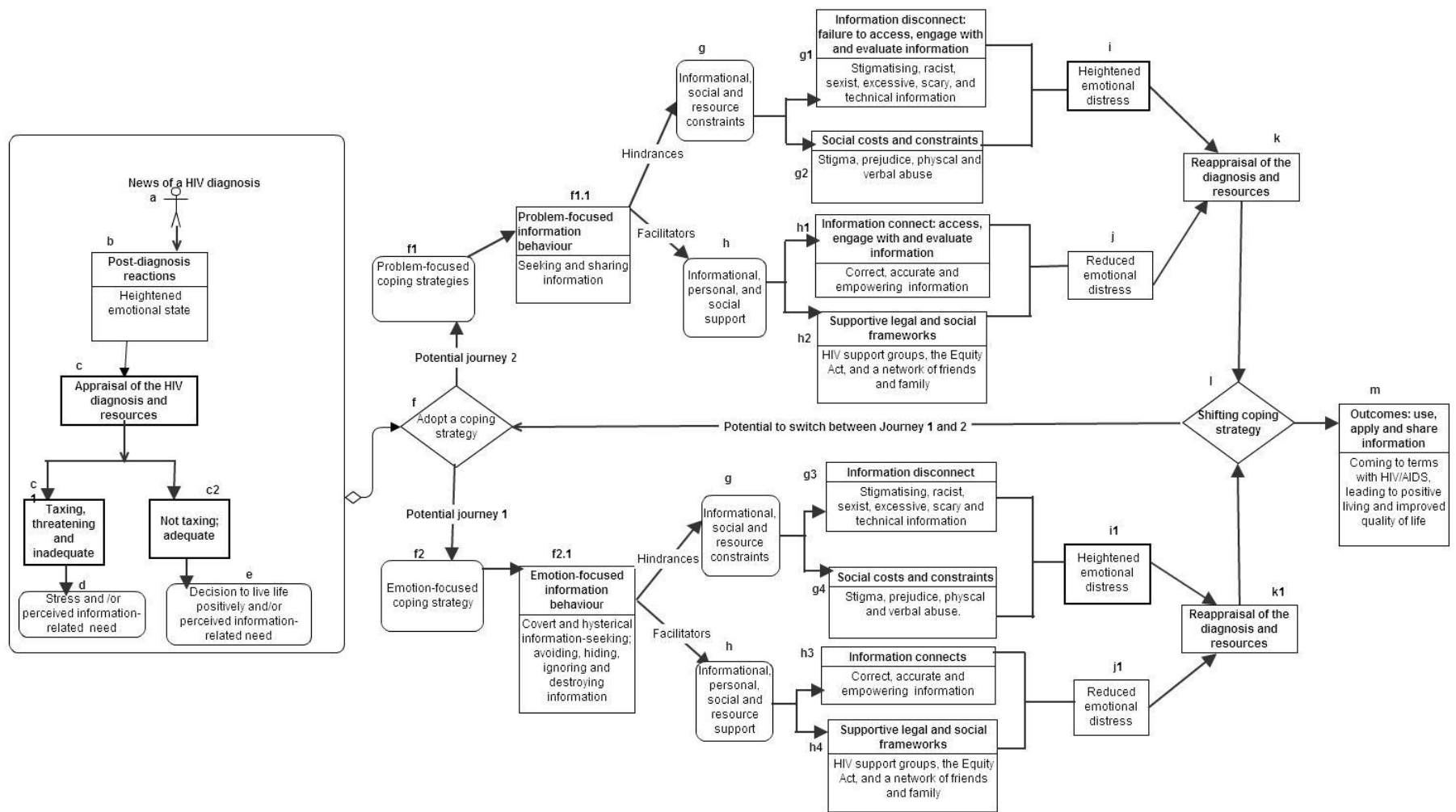


Figure 3 : Model of HIV/AIDS-related information

As depicted in Figure 6, the model starts with an actor. This may be either a person being given the results of an HIV test, or close member of the family who receives the news of an HIV diagnosis of a relative ('a'). The potential reactions to the diagnosis may include heightened emotional state ('b'). These underlie people's appraisal of the diagnosis and resources ('c').

The appraisal of the diagnosis as threatening and resources as inadequate (c1) may result in stress and/or HIV/AIDS-related information needs ('d'). On the other hand, if the diagnosis is appraised to be less threatening and resources to be adequate (c2), the actor may opt for positive living ('e'). The potential to need to cope with HIV/AIDS diagnosis by the actors is depicted as a coping strategy ('f'). The model suggests two potential journeys: emotion-focused ('f2') or problem-focused ('f1'). The model suggests that actors could exhibit various forms of information behaviour depending on the coping strategy they adopt; which could be emotion-focused information behaviour ('f2.1'), or problem-focused information behaviour ('f1.1'). An example of each approach is given below in terms of two different journeys. As explained below, an actor may switch between types of journeys.

Journey 1.

The model suggests that, during the course of adopting emotion-focused strategies, an individual could encounter informational and social constraints ('g'), such as stigmatising, excessive, overly technical and scary information ('g3') and/or stigma, prejudice discrimination as well as physical and verbal abuse ('g4'). This can lead to heightened emotional distress ('i1').

Consequently, this actor could engage in emotion-focused information behaviour/coping strategies ('f2.1') such as hiding, destroying, avoiding information or hysterical and/or covert information seeking in order to cope with HIV/AIDS-related emotional distress and anxiety.

On the other hand, access to informational and social support ('h'), including experiencing information connects such as access correct, reliable and

empowering information ('h3') and /or obtaining social and legal support including access to HIV/AIDS support groups, legal support as well as support from family and friends (h4') may lead to reduction of emotional distress ('j1'). This could result in the actor reappraising the diagnosis ('k1'), and shifting the coping strategy ('l') from the initial emotion-focused coping strategies (f2') to problem-focused coping strategies ('f1'). This may result in a shift from emotion-focused information behaviour such as avoiding, hiding, destroying information ('f2.1'), to problem-focused related information behaviour such as seeking and sharing information ('f1.1'). The potential to switch between journey 1 and 2 indicate flexible flows from process to process. Possible outcomes include coming to terms with HIV/AIDS and improved quality of life ('m').

Journey 2.

Alternatively an actor who adopts a problem-focused strategy could experience informational and social constraints ('g') such as anticipated and experienced stigma and discrimination ('g2') as well as information 'disconnects' ('g1'). These constraints lead to frustration, embarrassment and emotional distress ('i'), and lead to reappraisal of the diagnosis and resources ('k'). Thus the individual, who initially employed problem focused-strategies ('f1'), may opt to shift strategy ('l'), and engage in emotion- focused related information behaviour ('f2'), such as destroying, avoiding and hiding information.

Possibly, unsuccessful attempts to use information may spark a return to engagement at a deeper level in which it is more fully comprehended. The potential to switch between journey 1 and 2 indicate flexible flows from process to process.

Alternatively, an actor who initially adopts problem-focused strategies ('f1') may experience facilitators ('h') such as informational ('h1') and social ('h2') support and may experience a reduction in emotional distress ('j'). This could lead to reappraisal of the diagnosis and resources ('k'). Such an actor could engage in further problem-related information behaviour such as seeking and sharing HIV/AIDS-related information ('f1.1') and experience outcomes such as coming to terms with HIV and improved quality of life ('m').

Reappraisal of illness and resources can occur at any time in the course of living with HIV/AIDS and/or caring for a close member of the family. Reappraisal may result in shifting strategies; that is, a move from problem-focused coping to emotion-focused coping strategies and vice versa.

Reappraisal can stimulate problem-focused coping which could result in seeking information. However, encountering resource constraints may lead to uncertainty and frustration and can result in further problem-focused coping strategies such as seeking help from expert patients, or emotion-focused strategies such as giving up any efforts to look for information. If not frustrated by resource and social constraints, problem-focused efforts such as information seeking may help to restore lost confidence and transform respondents into valuable information sources and information providers. Section 8.8 provides the theoretical explanation to the model.

8.8. Theoretical explanation of HIV/AIDS-related information behaviour

Subsections 8.8.1-8.8.7 consists of the theoretical explanation of the patterns of information behaviour described in figure 6.

8.8.1 The news of an HIV/AIDS diagnosis

The news of a diagnosis of a life-threatening and damaging illness, that is, HIV/AIDS is not only devastating and stressful to the person who is diagnosed with HIV, but also to close family members.

As described in this study, an HIV diagnosis not only threatens the very reason for living but it could also be overwhelming, traumatising and damaging to people's well-being as depicted at 'c' of the model. It is thus not surprising that, upon receiving the news of an HIV-positive diagnosis, PI/A HIV/AIDS were devastated by perceived imminent death. Consequently, HIV diagnosis was appraised as life-threatening, stressful and taxing, which resulted in emotion-focused strategies such as avoiding information as shown at point 'f2' in Figure 6. This observation is supported by Lazarus and Folkman (1984), who defined stress

as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being. Lazarus and Folkman's (1984) definition of psychological stress helped to explain post-diagnosis HIV/AIDS-related psychological stress in relation to the different forms of information behaviour that PI/A HIV/AIDS adopted in the course of living with HIV. Therefore Lazarus and Folkman's (1984) *Stress Appraisal and coping* theory provides the theoretical explanation for the potential forms of information behaviour that people may adopt in an HIV/AIDS-related information context.

8.8.2 Appraisal of HIV diagnosis and resources

In keeping with Lazarus and Folkman's (1984) *Stress Appraisal and coping* theory, the respondents' appraisal of the illness influenced the coping strategy they adopted as depicted at points 'f1', and 'f2'. For example, all respondents appraised an HIV diagnosis as threatening and endangering to their well-being because their life span and future quality of life had been threatened. Thus the diagnosis was traumatic, stressful and disruptive because it was not only threatening but it jeopardised people's well-being.

8.8.3 Coping strategies and associated information behaviours

Since living with HIV is a lifelong journey, the need for cognitive and behavioural efforts in the form of coping strategies to manage stressful demands posed by the diagnosis is inevitable.

Coping is defined as constantly changing cognitive and behavioural efforts to manage specific internal and/or external demands that are appraised as taxing and exceeding the resources of the person (Lazarus and Folkman, 1984). Lazarus and Folkman's (1984) definition is appropriate for the current study because it is concerned with anything that a person does or thinks in a particular context, regardless of how well or badly it works, and avoids equating coping with mastery. Hence, coping is not about mastery over the environment. It allows the person to tolerate, master, minimise, accept or ignore what cannot be mastered. The model shows that coping could be directed at managing or altering the

problem causing the distress, also known as problem-focused coping, and/or regulating emotional responses to the problem, also known as emotion-focused coping (Lazarus and Folkman, 1984; Lazarus, 1993). Arguably, different forms of emotion-focused coping strategies such as avoidance, blaming self, seeking social support, and denial, were employed to maintain self-esteem, hope and optimism, in the face of irremediable HIV infection.

8.8.4 Emotion-focused coping strategies

This section describes emotion-focused information-related information behaviour such as information avoidance as well as covert and hysterical information seeking.

8.8.4.1 INFORMATION AVOIDANCE

Information avoidance is an emotion-focused information behaviour that could be employed to cope with HIV/AIDS-related health threats, social stigma and emotional distress.

For example, a person newly diagnosed or whose close family member is diagnosed with HIV/AIDS, may enter a period of denial and refuse to take on board the reality of being affected by the disease as depicted at point f2.1. A person in such a state of denial may not perceive that they require any HIV/AIDS-related information, and may avoid and /or ignore information. A less extreme reaction may be, while acknowledging the diagnosis, not wanting to think about the disease – either through fear (in which case, even information with which the person comes into contact may be actively ignored and avoided), or simply because the person is feeling well and perceives no need for information at the present time (in which case, he or she simply does not seek information). A person may hide or discard information in order to conceal his or her HIV status if s/he fears a negative reaction from others (for example, the wider community, strangers, colleagues, friends and family members). Arguably, people faced with the life-threatening HIV diagnosis and the associated HIV/AIDS-related social-stigma can employ emotion-focused coping strategies such as avoiding and ignoring information to reduce emotional distress. For instance, PI/A HIV/AIDS

reported that, even though they knew that they could get valuable information from the Internet or the HIV support group, they did not access such sources due to fears that family members and /or friends would discover their HIV status or that of a close family member. In such instances information was sought covertly.

This finding is consistent with previous research such as Lazarus (1991), Lazarus and Folkman (1984), and Lazarus (1993), where it was observed that emotion-focused coping strategies could consist of cognitive processes, such as avoidance, minimisation, distancing, selective attention, and positive comparison directed at regulating emotional distress. Their observation that emotion-focused coping strategies mainly occur when there has been an appraisal that nothing can be done to modify harmful, threatening or challenging conditions, are consistent with the findings of the current study in which people adopted emotion-focused strategies such as refusing to acknowledge the HIV diagnosis, or opting to not seek information about HIV/AIDS, because they initially appraised the HIV diagnosis as taxing, threatening and thus exceeding their capacity to do anything to modify or change the HIV status.

8.8.4.2 COVERT INFORMATION SEEKING

Covert information seeking as depicted at point 'f2.1' is also a form of desperate emotion-focused coping strategy employed by PI/A HIV/AIDS to obtain information while avoiding stigmatising tendencies and moralistic judgments from family, friends and members of the community. The analysis of data revealed that people who experience discomfort about being seen to have any association with HIV/AIDS, including accessing and using HIV/AIDS resources, materials and services in public, sought information clandestinely or covertly. This unique information behaviour illustrates the importance of information in the lives of PI/A HIV/AIDS.

8.8.4.3 HYSTERICAL INFORMATION SEEKING

Hysterical information seeking as depicted in 'f2.1' is an emotion-focused coping strategy that may be employed when people became over-vigilant and panicky

about the HIV diagnosis. In the context of this study, hysterical information seeking describes the nature of information seeking people may engage in under extreme emotional distress, fear, shock and anxiety. The current study revealed that hysterical information seeking could result in increased anxiety as people may not be in a state of mind to engage with information and/or understand the messages being conveyed in the information.

In summary, excessive psycho-social threats, such as fear of moralistic judgments from family, friends and the wider community accounted for forms of emotion-focused information-related coping behaviours such as avoiding and hiding information, as well as covert and hysterical information seeking. Although emotion-focused coping could reduce emotional distress, it is important to bear in mind, that over-concentration on these strategies could result in insufficient attention to problem solving and jeopardize the quality of life. The above finding is consistent with Janis and Mann (1977), Lazarus and Folkman (1984), and Anderson (1977), who argued that, at high levels of stress, emotion-focused forms of coping predominate. With regard to the relationship between emotional distress and information behaviour, Janis and Manns (1977), in their model of conflict and decision making, argued that excessive threat could lead to ineffective information gathering and evaluation and consequently lead to hyper-vigilance. They observed that excessive threat could interfere with problem-based forms of coping through its effect on cognitive functioning and capacity for information processing. Similarly, Lazarus and Folkman (1984) reported a reduction in patients' information processing and problem solving capacity when doctors gave them bad news. Thus a patient's ability to hear what the physician has to say about prognosis, procedures and treatment could be critically impaired by the level of threat engendered by the diagnosis.

The proposed model suggests that anxiety associated with high levels of stress could lead to over concentration on emotional and defensive coping mechanisms and insufficient attention to problem-based coping strategies. Consistent with this reasoning is Lazarus (1999), who observed that the greater the threat, the more primitive, desperate or regressive the forms of coping tend to be, and the more limited the range of forms of problem-focused coping.

However, Collins et al.(1983), and Lazarus (1993), observed that under conditions where nothing useful can be done to change the situation, adopting rational problem-solving efforts can be counter-productive and are even likely to result in chronic distress when they fail. In such circumstances, emotion-focused strategies could offer the best coping choice.

8.8.5 Problem-focused coping strategies

This section describes problem-focused information-related information behaviour: seeking and sharing information.

8.8.5.1 SEEKING AND SHARING INFORMATION

Rather than ignoring or avoiding information, a person may wish to learn more about the disease in order to better understand how to manage it, to maximise his or her own well-being and to understand how to minimise any threats to others; for example, via infection. He or she may also seek and/or share information which s/he hopes will counter ignorance, misinformation or stigma on the part of others with whom s/he has contact as depicted at point 'f1.1'. Consistent with this reasoning is Lazarus and Folkman (1984), who observed that problem-focussed coping strategies could be employed to manage or alter the problem causing distress. In the context of the complex HIV/AIDS-related information needs, people can seek information from a wide range of sources (the Internet, websites, databases, medical practitioners, booklets and expert patients, HIV support groups, etc.) to obtain and corroborate knowledge in order to make important decisions and maintain a good quality of life. Thus it is not surprising that information was described as a crucial resource for people faced with the life-threatening illness – HIV/AIDS (Huber and Cruz, 2000; Hogan and Palmer, 2005a; Tiffany, 2010; Zukoski et al., 2011). However, information disconnects such as information being excessive, stigmatising, written at the wrong level, contradictory, overwhelming and one that 'others' HIV, as depicted at point 'g1', and social constraints such as stigma and discrimination 'g2', could lead to emotional distress, depicted at point 'i' on the model, and undermine efforts to engage in problem-based coping strategies. Chapter nine suggests the need for interventions that are geared towards reducing HIV/AIDS-related information

disconnects and social stigma, to facilitate interaction with HIV/AIDS-related information. Such interventions are particularly important for a group of information users who need accurate, reliable and up-to-date information to make choices and decisions that pertain to life and death.

8.8.6 Shifting coping strategies

The model at point 'h3' attempts to illustrate that typical HIV-related information behaviour could entail switching between seeking, sharing, hiding, avoiding and destroying information. PI/A HIV/AIDS for example, could engage in problem-focused strategy entailing information seeking to inform themselves about HIV/AIDS. During the search process they could encounter contradictory and worrying information, consequently experiencing anxiety and distress. The effect of this could be reverting to emotion-focused strategies such as hiding and avoiding information, as well as covert information seeking. For example, people switched from seeking and sharing information to hiding or avoiding or destroying information when they encountered information disconnects, and /or when engaging in information seeking was perceived to have disastrous emotional effects such as anxiety and distress, and /or when they experienced or anticipated social costs such as abuse, prejudice, discrimination and stigma, as depicted at points 'g1' and 'g2'.

On the other hand, a person could choose to avoid seeking HIV/AIDS-related information because s/he fears getting emotionally distressed by learning more about HIV/AIDS as illustrated at point 'f2.1' on the model. When exposed to accurate information ('h3') s/he could find that living with HIV is not as hideous as always portrayed. This may lead to a reduction in emotional distress and an increased desire to learn about HIV/AIDS, thus making a shift from emotion-focused information behaviour ('f2.1') to problem-focused information strategies ('f1.1') such as seeking and sharing information, to learn about HIV and clarify myths about HIV/AIDS. This could have outcomes such as coming to terms with HIV/AIDS, moving on with life and/or improved quality of life, as depicted at point 'm' of the model. The above accounts illustrate that emotion-focused strategies were adopted to make life more bearable by avoiding realities which might prove to be overwhelming.

As evidenced from the analysis of data and discussion, both problem-focused and emotion-focused coping strategies can, to a certain extent facilitate and/or impede each other. For example, people who employ emotion-focused strategies may block any attempts to employ problem-focused coping strategies. On the other hand, when problem-focused strategies, such as information seeking and information sharing, are employed, and are not hindered by resource constraints, they can facilitate further problem-focused coping strategies like information sharing through activities such as talk shows, school outreach sessions, and community outreach information sessions, that help to create HIV awareness. However, resource and environmental constraints such as stigma, discrimination, and information disconnects could impede problem-focused coping and lead to hiding and avoiding information. For example, the respondents' problem-based efforts to cope with HIV through seeking information (about HIV, medications, HIV transmission, social life and relationships, socio-economic and legal information, general welfare information) can be constrained by HIV/AIDS-related information disconnects. This confirms Lazarus and Folkman's (1984) observation that the ways in which people actually cope also depend heavily on the resources that are available to them and the constraints that inhibit the use of these resources in a specific encounter. For example, when the respondents were faced with information disconnects during problem-focused information-seeking based coping, they experienced uncertainty and increased anxiety and reverted to emotion-focused coping strategies to avoid becoming upset or frightened.

8.9. The anatomy of information connects and disconnects

Behaviour relating to information entails a multitude of processes, any one of them capable of resulting in a 'disconnect' (an experience which is not deemed useful). A 'connect' may require a number of processes to have been successfully completed. As explained below, these processes are not necessarily sequential, and each may be revisited in an iterative process. The different processes do not represent a fixed or sequential set of stages. While one process may logically precede another (e.g., evaluating information cannot take place unless and until one has engaged with it), the fact that the same process may be applied at different levels means that they do not necessarily occur in any fixed sequence.

For example, information may be serendipitously encountered by, or given to, a person without necessarily their having first perceived a need for it. Information may be used without the person necessarily having fully engaged with (read and understood) it. Possibly, unsuccessful attempts to use it may spark a return to engagement at a deeper level in which it is more fully comprehended. The same may apply to evaluation; information used or rejected being returned to for deeper evaluative processing. A ‘disconnect’ may be triggered at any of the processes, which may be characterised as follows:

8.9.1 Perceive an information-related need

This relates to the perception by an individual of some need which may be addressed by some form of information behaviour. The individual may or may not be aware of the information behaviour implications of the need. An information-related need may be (but is not necessarily) an information need (i.e., a need which may be satisfied by information). People may differ in the extent to which they perceive a need for information, particularly during the period immediately after diagnosis. Some may want to find out as much as they can about the disease (to learn how best to manage it, and/or to protect others), while others may want to avoid information (if they feel it will alarm them, or if they are feeling well, they feel it would only serve needlessly to remind them of their HIV status).

8.9.2 Seek or encounter information

Information may be actively sought in relation to perceived needs, encountered serendipitously, or given to a person (e.g., by a service provider). People may come into contact with information in a variety of planned and unplanned ways. They may actively seek information in relation to a perceived need, encounter information serendipitously, or have it given to them. Failing to come into contact with required information in response to a perceived need was a ‘disconnect’ mentioned by a number of respondents. Taking too active an approach to information seeking immediately after diagnosis was reported by others, leading to information overload. Some people who perceive an

information need may nevertheless actively seek to avoid coming into contact with information, possibly through fear of alarm.

8.9.3 Engage with information

Comprehension entails actually engaging with (e.g., reading a textual, or watching a visual medium) information with which one has come into contact. A person may not necessarily engage with, and try to understand, information with which s/he has come into contact. Just as a person may avoid coming into contact with information, s/he may not wish to engage with it for similar reasons. For example, a person may be given information by a support worker or information provider, and feel that to engage with it would cause worry or alarm. Another may feel that s/he simply had no need to engage with it because s/he feels well at present, and would prefer to engage at a time when s/he feels more of a need. A disconnect may occur if an attempt to comprehend fails and/or information is stigmatising, racist and sexist. A number of respondents reported cases where they could not engage with information because it was either written at an inappropriate level for them or stigmatising such as being racist, and sexist.

8.9.4 Evaluate information

Assuming comprehension, information may then be evaluated in terms of the extent to which it is or is not valuable. A disconnect may occur if information is negatively evaluated. This may result from a variety of mismatches between the receiver and the comprehended content of the information, which may be perceived as, for example, incorrect, irrelevant, alarmist or biased. Unvalued information is unlikely to be used, while valued information may be applied.

8.9.5 Use/apply information

Information deemed valuable may be applied in some way – by using it oneself and/or sharing it with others. Information that has increased understanding of the disease may be used to better manage it, and to avoid the risks of infection to others. Information may also be shared in order to inform and educate others; for example, to enable them to protect themselves from infection through understanding of the risks, and to counter ignorance, misinformation, or

prejudice. Information may also be shared to provide mutual support. Information that is not deemed useful may be discarded. However, information that a person concealed and/or discards may be useful to that person, since these information behaviours may be exercised in order to maintain privacy and safeguard against victimisation, discrimination and abuse.

8.10. Conclusion

Based on the work on stress and coping by Lazarus and others (Lazarus and Folkman, 1984; Lazarus and Folkman, 1986; Lazarus, 1991; Lazarus, 1993; Lazarus, 1999), this study proposes that HIV/AIDS-related information behaviour can best be understood in the context within which it takes place. Although it was outside of the scope of this study to examine the extent of information behaviour between PI/A HIV/AIDS, the data from each group provided evidence that the behaviours and actions PI/A HIV/AIDS took to cope depended on the details of the context in which they lived, and/or in which the disease occurred, and changed over time. This accounts for apparent information-related paradoxes among persons living with HIV. For example, a person could engage in seeking and sharing information and/or hiding or even destroying information depending on his or her appraisal of the anticipated harm, threats or benefit resulting from interaction with HIV/AIDS-related information. Consistent with this reasoning is Lazarus's (1993) paper, which suggests that an appreciation of the context in which this disease occurs could help to generate understanding about the 'lived information experiences' of persons infected with HIV, including forms of HIV/AIDS-related information behaviour that could be employed. This could inform the design and implementation of HIV/AIDS-related information interventions.

The study also points to a need to pay attention to the shifting nature of information behaviour. This is particularly important as people's appraisals of the resources and illness change, consequently the coping strategies and information behaviour to be adopted changes in accordance with the situational contexts. Lazarus's (1993) definition of coping as on-going cognitive and behavioural efforts made to manage (including mastering, reducing or tolerating) specific

internal and external demands, and conflicts among them, was useful in generating understanding of the adaptive and non- adaptive cognitive and behavioural information-related efforts that PI/A HIV/AIDS employed to manage (reduce and/or tolerate) the debilitating effects of HIV/AIDS.

The forms of information behaviour identified in the current study are not described as positive or negative, although some behaviour could be deemed more beneficial than others. This is consistent with Lazarus (1993), who observed that there is no universally good or bad coping process, though some might more often be better or worse than others.

In addition to identifying information behaviours within the HIV/AIDS context, the model has drawn our attention to forms of information seeking which have received only scant attention in the library and information science research literature, such as covert and hysterical information seeking. It has also illustrated that HIV/AIDS information behaviour is an on-going lifelong dynamic process. The shifting strategies employed have indicated that HIV presents PI/A HIV/AIDS with complex information needs over the course of living with the disease, and this accounts for a wide range of information behaviours among this group of information users. Consequently HIV information behaviours do not follow a predictable pattern. The dynamics and changes that characterise peoples' coping with HIV are a function of continuous appraisal and reappraisal of the illness and of resources at their disposal, as stressful encounters unfold. Thus a person at certain times relies more heavily on one form of coping strategy/information behaviour than others.

To summarise: this chapter has discussed the lived information experiences of PI/A HIV/AIDS, and developed a model of HIV/AIDS-related information behaviour, including drivers and outcomes. Chapter nine will discuss the implications of these experiences on practice, strategy and policy, and will present recommendations for further research.

CHAPTER 9- CONCLUSION AND IMPLICATIONS

9.1. Summary of the study

This chapter presents a brief overview of the study (section 9.1), describes the key findings (9.2) and highlights the implications of the findings for Library and Information Science educators, practitioners, and the wider scholarly community (9.3). It goes on to discuss the limitations of the study (9.4), and to make suggestions for future research (9.5). Finally, the conclusions of the study are presented (9.6).

9.1.1 Research focus and aim

The current research sought to explore the ‘lived information experiences’ of persons infected with, or affected by HIV/AIDS (PI/A HIV/AIDS), along with their HIV/AIDS-related information behaviour and factors that shape it. It sought to gain a sensitive and intimate appreciation of the information experiences, including frustrations, challenges, and dilemmas, ‘connects’ and ‘disconnects’ of this group of people. In so doing, the study sought to generate understanding of the everyday information behaviour of PI/A HIV/AIDS which might be useful in informing attempts to improve the design and provision of information services and products that are sensitive to the complexities of accessing and using information in the context of this life-threatening and stigmatising chronic illness, i.e., HIV/AIDS.

9.1.2 Methodology and research approach applied to the current study

Ethnographic methods were selected to study the information behaviour of this group because they are particularly well suited to unearthing complex phenomena, in marginalised social settings, among hard to reach populations. Ethnographic approaches helped the researcher to uncover what might otherwise remain hidden information experiences, particularly in settings characterized by stigma and discrimination. They enabled the generation of a rich picture through a thick description of the people’s HIV/AIDS-related ‘lived information

experiences', and generated rich insights into HIV/AIDS-related information behaviour and factors that shape it.

9.1.3 Summary of findings

The study revealed a number of distinctive information behaviours which appeared to be strategies for coping with a range of internal and external factors and circumstances, including reactions to diagnosis, stigma and the need to educate and inform both self and others. Information behaviours included not only information seeking, and sharing, but also covert and hysterical information seeking, as well as avoiding, hiding and destroying information. The key findings are discussed in more detail in section 9.2.

9.1.4 Contribution to knowledge

The interdisciplinary research reported here has made the following contributions to knowledge:

- The study has highlighted that information behaviour is very complex and not always rational as most models of information seeking and information behaviour have tended to depict it. In light of the above a model has been developed based on empirical evidence of the 'lived information experiences' of PI/A HIV/AIDS. The current study has therefore moved beyond relatively reductionist and simplistic representations of information behaviour by addressing the finer details of the complexities of human information behaviour, particularly in life-threatening and stigmatising health-related information contexts such as HIV/AIDS. The model provides a framework for thinking about HIV/AIDS-related information behaviour, and a statement of relationships among theoretical propositions. The model not only describes the forms of information behaviour people may adopt but also seeks to explain why such behaviours may be adopted in different contexts. The model thus has the potential to predict HIV/AIDS-related information behaviour. However, the predictive ability of this model would require testing in a large-scale longitudinal quantitative study.

- The study has also pointed to a need to pay attention to the shifting nature of information behaviour. This is particularly important as people's appraisals of their resources and illness change over time. Consequently the coping strategies and corresponding information behaviour adopted can change in accordance with situational contexts. The study has also illustrated that HIV/AIDS information behaviour is an on-going lifelong dynamic process. The practice of adopting shifting strategies has indicated that HIV presents PI/A HIV/AIDS with complex information needs and social dilemmas over the course of living with the disease, which accounts for a wide range of information behaviours among this group of information users. Consequently HIV information behaviours do not follow a predictable pattern. The dynamics and changes that characterise people's coping with HIV are a function of continuous appraisal and reappraisal of the illness and of resources at their disposal, as stressful encounters unfold. Thus a person at certain times relies more heavily on one form of coping strategy/information behaviour than others.
- The study has identified relatively deep and fine detailed human information behaviour within the HIV/AIDS context: covert and hysterical information seeking and destroying and hiding information (also described as emotion-focused coping strategies) which has received only scant attention in the library and information science research literature.
- The study has drawn attention to the effect of one's emotional state on information behaviour and suggested a need for information professionals, information service designers and providers to understand information users at deeper levels.
- The study has highlighted a number of information disconnects that impede access to, and use of, information. It has generated understanding of the nuanced ways in which interactions with information may be enhanced or impeded. Such knowledge could inform the design and implementation of information related interventions that are sensitive and responsive to information users faced with life-threatening and stigmatising conditions.
- Rather than stopping at the pre-theoretical stage, the current study has advanced to specify relationships by employing theoretical propositions from

Lazarus and Folkman's Stress Appraisal and Coping Theory (1984) as well as Goffman's (1963) Stigma Management theory to explain HIV/AIDS-related information behaviour. This is arguably an approach that has hitherto not been adequately applied to library and information science research.

An initial practical impact of this study was a successful 3-month community outreach project proposal 'Fighting HIV on an information front', funded from the Roberts PGR Placement Fund.

9.2. Key findings

Section 9.2 summarises the key findings and sets the scene for section 9.3, in which the implications of the findings are discussed.

9.2.1 Social stigma is a major concern for PI/A HIV/AIDS

Stigma continues to be a real concern for PI/A HIV/AIDS as discussed in Chapter six. In the view of the respondents, HIV/AIDS-related fear and discrimination, the off springs of stigma, are based on ignorance and lack of information.

The study has shown that when it comes to life-threatening stigmatised illnesses, interaction with information can, to a great extent, depend on the anticipated and experienced social costs. Social stigma, on the part of respondents' significant others and /or people who have contact with them, emerged as a major hindrance to access to, and use of, HIV/AIDS-related information. This issue was raised by all respondents at one time or another in their interviews. The respondents responded to social stigma by adopting information behaviour in a manner consistent with Lazarus and Folkman's (1984) stress emotion and coping theory and – Goffman's (1963) stigma management theory. Some of these included seeking information under cover, also described as covert information seeking in the current study, as a safeguard against stigmatising tendencies.

In the view of the respondents, nowadays the picture of HIV is much more complex and nuanced than it was 30 years ago. They expressed concerns that, although effective-long term treatments can enable people diagnosed with HIV to lead apparently normal lives, stigma surrounding the virus is still pervasive. They

attributed the widespread stigma to inadequate knowledge and lack of awareness of HIV/AIDS amongst the population as a whole. Thus, for a substantial proportion of PI/A HIV/AIDS living in the UK, prejudice and stigma remain a reality (Terrence Higgins Trust, 2001; House of Lords Select Committee on HIV/AIDS in the United Kingdom, 2011). Stigma not only has a substantial impact on people's physical and mental health, but it can also block HIV/AIDS-related information dissemination, and undermine efforts to prevent and manage the disease.

The study has shown that HIV support organisations continue to play an important role in the post-diagnosis lives of PI/A HIV/AIDS by providing a stigma-free environment. Similarly, the positive relationship between PI/A HIV/AIDS and health workers seemed significant to the wellbeing of the former. However, the pervasive social stigma and discrimination they anticipated and /or experienced in healthcare and social settings not only adversely affected their self perception and mental health, but also inhibited them from accessing services offered that they potentially needed, including information.

The findings of this study are corroborated by Mehra and Dessel's (2011) study in which Directors and Managers of public libraries attributed the patron's reluctance to talk about HIV/AIDS, and to discuss what information they needed, to pervading stigma and prejudice associated with the disease. Their study which revealed that library users within the study sample were happy to ask for information on other health-related concerns such as reproductive health, autism, cancer, but not HIV/AIDS confirms the importance of the current study whose findings suggest a need for interventions that can improve access to and use of HIV/AIDS-related information.

9.2.2 Information 'disconnects' are a significant issue

Information 'disconnects' emerged as a significant hindrance to access to and use of HIV/AIDS-related information in this study, and this is a novel finding from this research. Some of the information 'disconnects' that were identified include unintelligible, contradictory, over-dramatised, stigmatising or excessive information as well as information that 'others' HIV/AIDS. All respondents in

this study could readily recall one or more disconnects, suggesting that they are commonly experienced by members of the group studied. Having come into contact with information, a person may experience a 'disconnect' at the stage of engagement, in which s/he may find that it is written at too technical a level to allow full comprehension. Even when information is understandable, if resources employ phrases and terms with incriminating, judgemental, moralistic, sexist or racist connotations (as discussed in Chapter Seven) effective interaction with information could be hindered.

The respondents expressed concern that information disconnects, especially misinformation, lack of detailed knowledge about HIV/AIDS in the UK, and information that 'others' the virus may result in a low perception of risk and a false sense of security and complacency among the general population, which may potentially increase the risk of HIV transmission.

A severe lack of HIV/AIDS-related information has resulted in deteriorating levels of HIV/AIDS awareness and sustained levels of stigma that not only prevents people from taking HIV tests, but also makes the lives of PLWHA HIV/AIDS difficult and secretive. The importance of the current study is emphasised by Mehra and Dessel's (2011) study on issues and concerns related to the availability (or lack of availability) of HIV/AIDS information services in local public libraries, where interviews with managers and directors indicated no evidence to suggest any system-wide committee participation to develop health information services for PLWHA and reluctance of administration to allocate adequate budget resources for HIV information, particularly due to low usage statistics. This apparent lack of demand for HIV/AIDS resources amplifies the need for my work, which suggests that understanding of 'lived information experiences' (including information behaviour and factors that shape it) could inform the design and implementation of responsive information services and products, which could potentially improve access to and use of HIV/AIDS-related information.

9.2.3 The emotional state is a major determinant of HIV/AIDS-related information behaviour.

The study showed that information behaviour could represent a coping strategy designed to reduce emotional distress and anxiety. All respondents could recall instances of emotional distress on receiving the news of a positive diagnosis and during the course of living with or supporting a relative living with HIV. The study has shown that the information behaviours of people may differ considerably depending on a number of factors. These include personal circumstances and personal reactions. One person may react to diagnosis with denial, while another may immediately wish to seek information on how to minimise HIV/AIDS-related risk to those close to them. Depending on the anticipated reaction of people with whom they are in contact (which will depend on the extent to which such people are well or ill-informed about HIV/AIDS, and their attitudes to the disease), their resultant information behaviour may be geared either to concealment or to sharing and education.

9.2.4 HIV/AIDS-related information behaviour and needs are very complex and dynamic

Information-related needs and behaviour are likely to change over time, as are judgements of what information is, and is not, relevant and useful. For example, information on managing the disease may not be perceived as relevant by a person who is feeling well and who does not want to be reminded of the disease. Such a person may opt to avoid further information. However, the same information may become extremely relevant at a time when an illness sets in and the person desires information on how to manage it. A person's receptivity to information immediately after the shock of diagnosis may be very different from that experienced after a substantial period of reflection and/or receiving social support. Thus information-related needs and behaviour may be highly context and time-dependent, potentially changing kaleidoscopically over time and in reaction to changing circumstances and events. The complex and varied forms of information behaviour identified among this group of individuals (discussed in Chapter five) illustrate the unique ways in which HIV/AIDS-related life

dilemmas, challenges and frustrations can influence access to, and use of, HIV/AIDS-related information

9.3. Implications

In the light of the key findings above, the study has implications in two main areas:

- reducing the social cost of accessing and using HIV/AIDS-related information; and
- reducing information disconnects and increasing information connects.

9.3.1 Reducing the social costs of accessing and using HIV/AIDS-related information

Elton John's keynote address at the 2012 international AIDS conference in Washington (Anderson, 2012), in which he stressed that although the disease is caused by a virus, the epidemic is caused by stigma, ignorance, and lack of compassion, echoed the findings of the current study. Although the United Kingdom's Equality Act 2010 Office for Disability Issues (2010) aims to protect disabled people and people with progressive conditions such as HIV/AIDS and provides for people not to be discriminated against or harassed because they have an association with a disabled person, the magnitude of stigma and other pressures of living with HIV/AIDS in the UK is still considerable (Terrence Higgins Trust, 2001; House of Lords Select Committee on HIV/AIDS in the United Kingdom, 2011). Similar findings are reported in Mehra and Dessel's (2011) study that was conducted in Knoxville, United States. They reported that over the past three years HIV/AIDS-related 'judging', 'shunning' and discrimination had persisted. Pervasive fear of HIV/AIDS, lack of knowledge, and religious, cultural, and social norms and beliefs have been cited as the causal factors of HIV/AIDS-related stigma and discrimination against PI/A HIV/AIDS (Abdool Karim, 2011; House of Lords Select Committee on HIV/AIDS in the United Kingdom, 2011; Mehra and Dessel, 2011). Some ways of reducing the

social cost of accessing and using HIV/AIDS-related information are discussed in the next subsections below.

9.3.1.1 LEGISLATION

The results from the current study suggests that it would be beneficial to enforce legislation such as the Equality Act (2010), which aims to reduce HIV/AIDS-related stigma and discrimination, in order to create a social climate in which stigmatisation and discrimination are not tolerated and are reported to the appropriate authorities .

This could help to regulate other people's actions and reactions towards PI/A HIV/AIDS and enforce the imposition of penalties. Thus stigmatisation and discrimination would constitute a breach of basic human rights that could result in prosecution. When concretised in civil rights this could help effectively to prohibit HIV/AIDS-related stigmatisation and discrimination and protect PI/A HIV/AIDS accordingly.

The police could provide a reporting system for people to report complaints of HIV/AIDS-related stigma and discrimination as is the case with 101 for reporting complaints of antisocial behaviour. This measure could help to create a culture where people can report HIV/AIDS-related discrimination and stigma even in the absence of an eye witness. Police should take such cases seriously, make thorough investigations and provide support to victims of stigma and discrimination and/or prosecute or caution the offenders, similar to racial hatred - related crimes, for example racially offensive comments on Twitter about footballer Fabrice Muamba, by a Swansea University student Liam Stacey, resulted in a prison sentence of 56 days. The study also suggests forging collaborative partnerships between the community, the NHS, HIV/AIDS support and advocacy organisations and the police in order to fight HIV/AIDS-related prejudice and stigma.

9.3.1.2 HEALTH AND SAFETY

The nature of the stigma and discrimination experienced by respondents in medical services suggest that the health and safety procedures should be reviewed

to incorporate HIV/AIDS. This could provide clear guidelines on dealing with HIV/AIDS patients in order to eliminate ad hoc, erratic and discriminatory decisions and practices.

It would be beneficial for the standards to be communicated to members of the public so that both the medical practitioners and service users are fully aware of them. The medical practitioners who do not possess adequate knowledge of HIV/AIDS require urgent training in order to meet the healthcare needs of PI/A HIV/AIDS.

9.3.1.3 PUBLICITY AND EDUCATION FOR PI/A HIV/AIDS AND MEMBERS OF THE GENERAL PUBLIC

Publicity and education about the realities of HIV/AIDS among members of the public could raise awareness about HIV/AIDS, reduce unnecessary fear, create an informed society and increase tolerance about HIV/AIDS. This is particularly important because the respondents attributed the wide-spread stigma and discrimination to lack of real understanding of HIV/AIDS transmission and the disease more generally.

There is also need for publicity and education for PI/A HIV/AIDS about the legal protection for PI/A HIV as well as for appropriate reporting and enforcement mechanisms for reporting acts of discrimination and violence in order to mitigate the worst effects of HIV/AIDS-related stigma and discrimination.

9.3.2 Reducing information disconnects and increasing information connects

As discussed in Chapter eight, the study showed that a complex set of variables may influence whether a given piece of information, at a given time, and expressed in a particular way, will or will not mesh with a person's needs and existing cognitive and affective knowledge structures to produce a 'connect' or a 'disconnect'. Understanding and taking account of such variables is desirable on the part of those seeking to bring PI/A HIV/AIDS into contact with information that is well matched to their needs, circumstances, physical, cognitive and affective states at a particular point in time. Thus, for example, even information evaluated objectively by doctors and/or information providers as accurate and up-

to-date will not necessarily result in a successful ‘connect’ if it is perceived as inappropriate, unintelligible or alarming, if it is accessed in the wrong setting, or if it comes at a time when the recipient may be suffering from information overload. Information disconnects may be reduced in the following ways, set out in the next sub-sections.

9.3.2.1 AMEND THE INFORMATION STRATEGY FOR PUBLIC HEALTH, ADULT SOCIAL CARE AND THE NHS IN ENGLAND TO INCORPORATE GENERAL HEALTH INFORMATION, ESPECIALLY HIV/AIDS INFORMATION, IN ADDITION TO CLINICAL INFORMATION

The frequency and impact of information disconnects identified in this study (as discussed in Chapters seven and eight) points to a need for amendments to the existing strategy to take into account consumer health information in addition to clinical records and information including Electronic Patient and Electronic Health Records (EPR and EHR) (Smith and Preston, 2000; Department of Health, 2012).

This study suggests that it could be beneficial for agencies such as the NHS, HIV/AIDS community groups, PI/A HIV/AIDS, and representatives from different segments of the wider community to work together in the amendment of the strategy so as to incorporate consumer information services, particularly HIV/AIDS-related information services. The information strategy could provide the infrastructure required to coordinate HIV/AIDS-related information creation, use and management for the purposes of improving HIV/AIDS patient care and eliminating duplication and waste in HIV/AIDS-related information services design and implementation, for better information resource use. It could also support the design and implementation of HIV/AIDS-related information interventions and services that are responsive to the needs of information users faced with a life-threatening, distressing and stigmatising illness; take into account the importance of the timing of information dissemination; and facilitate access to and use of HIV/AIDS-related information. A coherent information strategy could increase the potential of HIV/AIDS-related information to educate and empower PI/A HIV/AIDS and the wider community through knowledge about

HIV/AIDS. The strategy could increase awareness of HIV, demystify HIV/AIDS, and reduce unnecessary fear and hostility towards PI/A HIV/AIDS. This recommendation is consistent with Mehra and Dessel's (2011) research that was conducted in the United States on the role of Library and Information Science education in the development of community information services for People Living with HIV/AIDS (PLWHA), which suggested the need for building inter-professional and intra-professional ties to address the challenges faced in providing effective health information services to PLWHA.

The researcher also suggests putting in place an HIV/AIDS information consortium to coordinate the planning, design and implementation of the HIV/AIDS-related information strategy suggested above. This could be the responsibility of the Department of Health to initially convene a brainstorming workshop whose participants would be drawn from the NHS, researchers, HIV support groups and representatives from segments of the community. Such a workshop would select a committee that would be tasked with drafting the terms and conditions of the consortium, including the memorandum of cooperation and the constitution.

Thus the members of the consortium could elect a team of experts with technical knowledge and project management skills to make decisions about how, where and when investment in the information infrastructure may be most effective. The consortium could aim at developing an information culture in which all stakeholders in the fight and management of HIV/AIDS understand the importance of information, where informational aspects of all HIV/AIDS-related activities and policies are fully taken into account and which equips PI/A HIV/AIDS and the wider community to effectively harness information in the fight against HIV/AIDS.

Interventions to ensure sustainable dissemination of HIV/AIDS-related information are urgently needed, given that PI/A HIV/AIDS seek information to support decisions that pertain to life and death. The study suggests sustained availability of accurate, reliable and accessible HIV/AIDS-related information to enable PI/A HIV/AIDS and the wider community to have access to information required to make informed choices and decisions. This would also contribute to

the attainment of goal 6 in the *Framework for better living with HIV in England* which focuses on ensuring that all people with HIV have the information they need to make choices around their treatments, health and quality of life (Keogh et al., 2009).

In view of the number of information-related challenges identified in this study, and given that so many aspects of HIV/AIDS prevention and management are information-dependent, the study suggests that the information strategy for public health, adult social care and the NHS in England should articulate key principles of effective HIV/AIDS-related information management in order to minimise information-related challenges and risks posed by information ‘disconnects’.

Such an information strategy could have the following objectives:

- to make HIV/AIDS-related information more accessible (e.g. by creating a list of trusted HIV/AIDS-related websites, databases and internet-based resources or services. Such lists should be updated regularly);
- to reduce the cost of accessing and using information (e.g. by sending text messages on HIV/AIDS basic information);
- to improve the quality and reliability of information;
- to manage HIV/AIDS-related information so as to provide a citizen-focused information service that supports the prevention and management of HIV/AIDS;
- to implement and maintain an information management infrastructure which would support the development of reliable, robust, flexible and scalable electronic and print information products and services.

9.3.2.2 DESIGN AND PROVIDE INFORMATION SERVICES AND PRODUCTS THAT ARE SENSITIVE TO COMPLEX HIV/AIDS INFORMATION NEEDS AND BEHAVIOUR

In the context of a life-threatening and stigmatising illness like HIV/AIDS, people may be too anxious and distressed even to consider accessing and using any information, share information about their status, or even understand the information they are given (as discussed in Chapter eight). Thus emotional distress may not only hinder effective interaction with, or stop people from

seeking, information; it may also motivate emotion-focused coping strategies such as hiding information to reduce negative emotions and to cope with the threat posed by the illness.

A range of people may be involved in providing information to PI/A HIV/AIDS and mediating that information. These may include doctors, medical and social support workers and information professionals. As suggested above, the extent to which they may succeed in engineering interaction with information in complex cases may depend on the extent and intimacy of their knowledge of the people they are dealing with and their circumstances. They will also particularly need to be aware of the negative effects of certain factors and interactions between them, and how to anticipate and address them. When it comes to complex and intimate needs for information, there is a limit to the extent to which an information provider can be familiar with another person's cognitive and affective states, the complexities of his or her circumstances, including his or her social relationships, which may help to determine the way information is received and processed. Those people who do possess such knowledge are the PI/A HIV/AIDS requiring information.

To fully satisfy complex needs requires an intimate understanding of the users and their circumstances as well as up-to-date, accurate, relevant and valuable information from a wide range of sources. Unfortunately, inadequate understanding of the users of HIV/AIDS-related information, coupled with information 'disconnects' not only make satisfying complex needs a daunting task, but they could also jeopardise efforts to prevent and manage HIV/AIDS. The findings point to a need for the design and implementation of information services and products that are sensitive to the emotional distress that people may experience. Such interventions may enhance the contribution that information can make to the management and prevention of HIV/AIDS.

People in different roles (medical practitioners, health support workers and information professionals) may possess complementary skills, knowledge, and levels of access to people in need of information. No one role on its own can necessarily offer all the parts of the jigsaw. The implication for information professionals is that they need to liaise and interact with those in other roles to

ascertain how best to offer responsive and, where appropriate, proactive information provision and mediation. They will need to be sensitive to the potential complexities and difficulties involved in providing timely, relevant and useful information to PI/A HIV/AIDS and in helping them to access information for themselves and develop skills in so doing.

9.3.2.3 TRAIN LIS AND OTHER PROFESSIONALS INVOLVED IN THE PROVISION OF HIV/AIDS-RELATED INFORMATION ABOUT ISSUES REGARDING THE COMPLEXITIES AND SUBTLETIES ASSOCIATED WITH ACCESS TO, AND USE OF, HIV/AIDS-RELATED INFORMATION:

The researcher suggests that training /education should be provided to Library and Information Science (LIS) professionals and all people involved in information provision about the complexities and subtleties of health-related information needs and information behaviour as well as the challenges associated with access to and use of HIV/AIDS-related information. People involved in LIS education, information resource design, and community HI/AIDS-related information initiatives should be enlightened about the realities of information ‘disconnects’, stigma and prejudice and the marginalising climate in which access to and use of HIV/AIDS-related information occurs. Education and knowledge could enable LIS professionals and information resource designers to provide services and products that are responsive to the challenges and dilemmas faced by this group of information users.

Information service provision to PI/A HIV/AIDS should have as primary goals (a) supporting access to and sharing of HIV/AIDS-related information, and (b) facilitating provision of the right information to the right people at the right time for the right purpose. The key guiding principles of services (whoever is providing them) could include:

- understanding the HIV/AIDS-related information needs of PI/A HIV/AIDS and the wider community;
- helping PI/A HIV/AIDS to develop appropriate skills to enable them to access the information they need and to use it effectively;
- providing access to appropriate information resources;

- providing information systems and an infrastructure which make available appropriate and accurate information to PI/A and the wider community and facilitate information sharing;
- disseminating HIV/AIDS-related information services and products including use of popular media, such as TV, radio, the Internet and social media, print and audio-visual media.

Services could help PI/A HIV/AIDS by making sure that:

- there is high quality, reliable, accurate, up-to-date information about a full range of challenges and issues in suitable formats , and tone;
- the information is simple, and readily accessible;
- the information will not scare and /or stigmatise them;
- the information is not incriminating, judgemental, racist or sexist;
- personal information about PI/A HIV/AIDS will be treated in accordance with the Data Protection Act.

The aim of services could be to empower PI/A HIV/AIDS and other members of the community by:

- making available correct and up-to-date basic information about HIV/AIDS to demystify the condition;
- educating people about the realities of HIV/AIDS, including the routes of transmission and who is at risk of contracting HIV/AIDS
- reducing the stigma, prejudice and fear surrounding HIV/AIDS.

They could potentially help to reduce the ignorance, misconceptions and lack of real understanding of the realities of HIV/AIDS arguably experienced by the general population due to the current lapse in general education and sensitisation about HIV/AIDS.

9.3.2.4 OPTIMALLY EXPLOIT INFORMATION ‘CONNECTS’

One way to optimally exploit information connects could be ensuring that there is continued and sustainable availability of HIV/AIDS-related information. This suggests a need for deliberate efforts and investments devoted towards sustainable

and continuous visibility of HIV/AIDS information in public discourse and media for PI/A HIV/AIDS and the wider community, as opposed to the current trend where this information only comes out on 1st December each year, i.e., World AIDS Day.

Based on the findings of the current study, particularly the complex information needs, the researcher suggests developing a social media presence devoted to PI/A HIV/AIDS and HIV/AIDS-related information on platforms such as Facebook and Twitter. Thus, PI/A HIV/AIDS could be encouraged to join such groups, in addition to joining the usual support groups. Given that most people enjoy the interaction and anonymity they get from social networks such as Facebook, if HIV/AIDS-related information, including experiences, is collated and uploaded onto the group's page, PI/A HIV/AIDS could easily access and share information and experiences with other group members.

9.4. Limitations of the study

The study was based on the qualitative analysis of data provided by a relatively small purposive sample of PI/A HIV/AIDS in a particular community and geographic region. Thus the findings presented here cannot be generalised to the wider population of PI/A HIV/AIDS. Moreover since all respondents were recruited via one HIV support group, the findings may not be fully transferable to all PI/A HIV/AIDS in England, particularly those who do not attend HIV support groups.

Although data from other groups of people such as medical practitioners and members of the wider community, including neighbours and work colleagues of PI/A HIV/AIDS could help to corroborate the findings of this study, such corroboration was not within the scope of the present study.

Nevertheless, the findings of this study can arguably enrich our understanding of HIV/AIDS-related information behaviour and the factors that shape it – an area which has received inadequate attention in Library and Information Science research. It is the view of this researcher that this knowledge could inform the

development of more responsive and sensitive health-related information products and services for this population as described in section 9.3.

Given that the current study required the respondents to share their information experiences in relation to a life-threatening, stigmatising and socially undesirable pathological condition – HIV/AIDS and entailed talking about personal and sensitive issues to an interested listener, in some cases for the first time, it was important for the researcher to know that the experiences were truthful and not exaggerated. Indeed, the researcher's long-term informal involvement with the respondents during support group meetings, lunch clubs and women's groups, allowed her to participate in their daily conversations, some of which included the subject of the dilemmas, frustrations, and challenges they experienced in using and accessing HIV/AIDS-related information and the stigmatising experiences with family, friends and the wider community. It is reasonable to conclude that the experiences were not exaggerated. Similar dilemmas, frustrations and challenges have also been reported in other parts of the world, including China, the USA, Canada, Uganda, Nigeria and South Africa (McCain and Gramling, 1992 ; Herek and Capitanio, 1999; Kalipeni et al., 2004; Medley et al., 2009; Veinot, 2009; Zhou, 2009; Abdool Karim, 2011; Winskell et al., 2011; Zukoski et al., 2011). Together these factors help to corroborate the data generated from the respondents in this study.

Whilst it is acknowledged that the model presented here may not be the only one to fit the data, it is evidence-based, having been generated by applying a systematic and rigorous research approach. It is plausible, reasonable and potentially useful.

9.5. Future research

The findings reported here predominantly represent the information experiences of PI/A HIV/AIDS. Further ethnographic studies of the information needs and behaviour of PI/A HIV/AIDS as perceived by groups such as medical practitioners, information professionals, friends and neighbours of PI/A HIV/AIDS, and members of the wider community could help to generate models that might complement the one presented in section 8.7. Such a study might help

highlight barriers to information, as well as identify problems in attitudes of staff and the wider community. The findings could provide an opportunity to compare the perceptions and assumptions of such other groups. This might generate insights into similarities and differences that could be useful in informing the design and delivery of HIV/AIDS-related information interventions and services.

The current study has led to a proposed model of HIV/AIDS-related information behaviour. Future researchers could test this model in a large-scale quantitative study.

An ethnographic study of the information behaviour of PI/A HIV/AIDS who do not use an HIV support group's services could generate insights into the nature of their HIV/AIDS-related information needs and behaviour, including the challenges, dilemmas, frustrations, 'connects' and 'disconnects' they experience in accessing and using HIV/AIDS-related information. This knowledge could inform the design and implementation of information-related interventions that are sensitive and responsive to the needs of this group of HIV/AIDS-related information users.

Comparative ethnographic studies of the information behaviour of people faced with chronic illnesses such as cancer, diabetes, multiple sclerosis and HIV/AIDS could generate rich insights into the patterns of information behaviour for people faced with the realities of living with debilitating chronic illnesses. This could also generate an understanding of the drivers that shape the information behaviour and highlight the differences and similarities in the information behaviour exhibited in the different chronic illness related contexts. Such knowledge could inform the development of macro chronic-illness related information interventions that are sensitive to the complex patterns of information behaviour exhibited by these people.

Strategic and policy-orientated studies into stigma and discrimination against PI/A HIV/AIDS are urgently needed to identify, assess and map the current prevalence of HIV/AIDS-related prejudice and types of HIV/AIDS-related discrimination experienced in the UK. These could inform the implementation of effective interventions, including social and community mobilisation and

empowerment, as well as structural interventions, including laws and policies that protect PI/A HIV/AIDS.

9.6. Conclusion

The study has generated rich insights into HIV/AIDS-related information behaviour from an everyday HIV/AIDS-related information user's perspective in the UK – an area which has been little explored in mainstream Information Science research. Ethnographic approaches enabled the researcher to unearth the complex information behaviour that people could employ to cope with the complexities of living with HIV/AIDS, including ways in which their cognitive and affective states – as well as social relationships – could help to determine ways in which information is received and processed, and explain the forms of information behaviour exhibited by PI/A HIV/AIDS. This was possible through long periods of engagement with the respondents, coupled with open-ended interviews; both of which enabled the respondents to open up to the researcher and share personal and sensitive information in a way that could not be expected in response to a questionnaire or in a single structured interview.

Having explored the HIV/AIDS-related 'lived information experiences' of PI/A HIV/AIDS, the researcher has learnt from their accounts that many of them feel that HIV/AIDS-related information is a vital resource in the prevention and management of HIV/AIDS. However the findings have also demonstrated that environmental factors such as information disconnects and psychosocial factors such as emotional distress, discriminatory and stigmatising reactions from family, friends and the wider community, could compromise the value of information in the prevention and management of HIV/AIDS.

The range of information behaviours, such as seeking, sharing, avoiding, destroying and hiding, as well as covert and hysterical information-seeking, could be considered as tools in a toolbox. One or more tools could be used depending on the circumstances and context of the information user.

The findings have revealed a picture which may be useful to Information Science researchers and educators in encouraging them to review their perceptions of

information users and information resources. The assumption that if one is able to access information resources that are objectively accurate, then one's information needs are solved could be misleading. This could in fact be the beginning of problems as this information – although accurate – could be technically too advanced, too alarming, stigmatising or distressing. Thus a more sensitive and nuanced appreciation of people's information needs, and information sources that might be appropriate, is required. Consequently, Library and Information Science professionals, HCPs and others in close supportive roles should have training that equips them to be able to understand users at these deeper levels.

It is the view of the researcher that the findings of the study can potentially illuminate ways in which information services could be responsive to the needs of PI/A HIV/AIDS. They can also provide a basis for proposing recommendations for information management in health contexts, including health information design, and health information management practice, strategy and policy. It is also the view of this researcher that the model presented here of HIV/AIDS-related information behaviour, and factors that shape it can inform the development of more sensitive and responsive health and information services, programmes and policies. These could greatly enhance the role of information in the prevention and management of HIV/AIDS.

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APPENDICES

Appendix A: Literature review methods, sample search strategy and interlibrary loans

The literature reviewed for this thesis was conducted systematically. The inclusion criteria for chosen literature were:

- Works available in English;
- Works with a focus on seeking health-related information
- Works which focus on HIV/AIDS-related information;
- Works on HIV/AIDS
- Works and /or models or theories of information behaviour;
- Works on health behaviour models;
- The inclusion of “HIV/AIDS information” information seeking, or health information behaviour, in text or title;
- Work on coping and stigma

Given the interdisciplinary nature of the current study computer generated searches were conducted in health –related databases such as Medline and PsychINFO, social science databases like Web of Science and information science data base, e.g., LISA Web of Knowledge in order to obtain a broad perspective of information seeking and information behaviour, health information behaviour, particularly HIV/AIDS-related information behaviour and the models and theories in order to examine how the notion had been explored. The search strategy on Medline is included in appendix A2 to illustrate how searches were conducted by breaking searches into key concepts and phrases which were then combined using the Boolean logical operators- AND and OR.

Examples of terms that were used alone or in combination included information; health information behaviour; models, theoretical, health knowledge, attitudes practice/or health education/or information dissemination/or information storage and retrieval, information seeking, information behaviour, HIV; AIDS, HIV AIDS information, health behaviour models, information seeking models, models of information seeking behaviour. Data base searches were supplemented by general internet search using web Search Engines such as Google scholar. In addition the researcher obtained information from information packs, training manuals, leaflets and fliers, reports and websites generated by organizations that have a special focus on HIV/AIDS in the UK. Some of these include NAM, Terrence Higgins Trust, National AIDS Trust, Centre for HIV and sexual health.

Searches were conducted on the online STAR and STARPLUS catalogues of the University of Sheffield library for information resources on the subject area of this study. Hand searching for health- related resource materials was conducted in School of Health and Related Research (SchARR) library.

The researcher also employed backward chaining, which entailed perusal of the reference lists of each article in order to retrieve potentially relevant works that were not initially identified. In addition, citation searching was conducted to identify and retrieve relevant resource materials.

A total of 44 interlibrary loan requests, mainly in the area of HIV/AIDS and information were made. The list of interlibrary loans is also included in appendix A1 below.

Appendix A1: List of Interlibrary loan requests

File Edit View Help

Interloan > Interloan

Acquisitions Cataloguing Circulation Interloans

Search

ISBN, ISSN etc.

Continue F9

Bib ID

Bib. Search F8

Item

Requester 62004496565

Bor. Search F2

Request No

Status

Verified

Requester	Barcode	Author/Title	Date
Namuleme, Robinah Kalemeera	004496565	Cheryl Martens/HIV	20/05/2010
Namuleme, Robinah Kalemeera	004496565	Williamson, Kirsty/Research methods for students, aca	08/04/2011
Namuleme, Robinah Kalemeera	004496565	Richard H. R. Harper/Inside the IMF: an ethnography o	19/03/2010
Namuleme, Robinah Kalemeera	004496565	Harriet Deacon ; with Inez Ste./Understanding HIV/200	06/09/2010
Namuleme, Robinah Kalemeera	004496565	Encyclopedia of library and information science / - Dor	13/09/2010
Namuleme, Robinah Kalemeera	004496565	AIDS Weekly PLUS / - Female Condom importance kn	23/11/2010
Namuleme, Robinah Kalemeera	004496565	JAIDS Journal of Acquired Immune Deficiency Syndron	09/12/2010
Namuleme, Robinah Kalemeera	004496565	Ann Intern Med / - Risk for Occupational transmission o	09/12/2010
Namuleme, Robinah Kalemeera	004496565	Edited by Barbara M. Montgomer./Studying Interperso	04/03/2011
Namuleme, Robinah Kalemeera	004496565	Elfreda A. Chatman/Information world of retired women ,	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Amanda Spink/Information behavior : an evolutionary ir	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Grover, P/Library and information science research : / -	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Williamson, Kirsty/Research methods for students, aca	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Medical Reference Services Quarterly / - Information n	20/12/2011
Namuleme, Robinah Kalemeera	004496565	European Journal of Personality / - Transactional theor	04/01/2012
Namuleme, Robinah Kalemeera	004496565	South African Journal of Libraries and Information Scien	12/01/2012
Namuleme, Robinah Kalemeera	004496565	Cancer Nursing / - Breast cancer patients' use of health	30/01/2012
Namuleme, Robinah Kalemeera	004496565	AIDS Care / - Seeking information about HIV/AIDS: a q	30/01/2012
Namuleme, Robinah Kalemeera	004496565	Human Communication ResearchIII / - A Comprehensiv	13/02/2012
Namuleme, Robinah Kalemeera	004496565	Journal of Health Communication: International Perspec	11/04/2012
Namuleme, Robinah Kalemeera	004496565	Issues in mental health nursing / - Living with dying: cop	24/04/2012

Interloan > Interloan

Acquisitions

Cataloguing

Circulation

Interloans

Search

ISBN, ISSN etc.

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Item

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Request No

Status

Verified

Requester	Barcode	Author/Title	Date
Namuleme, Robinah Kalemeera	004496565	Encyclopaedia of library and information science / - Dor	13/09/2010
Namuleme, Robinah Kalemeera	004496565	AIDS Weekly PLUS / - Female Condom importance kn	23/11/2010
Namuleme, Robinah Kalemeera	004496565	JAIDS Journal of Acquired Immune Deficiency Syndron	09/12/2010
Namuleme, Robinah Kalemeera	004496565	Ann Intern Med / - Risk for Occupational transmission o	09/12/2010
Namuleme, Robinah Kalemeera	004496565	Edited by Barbara M. Montgomer./Studying Interperso	04/03/2011
Namuleme, Robinah Kalemeera	004496565	Elfreda A. Chatman/Information world of retired women ,	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Amanda Spink/Information behavior : an evolutionary ir	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Grover, R/Library and information science research : / -	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Williamson, Kirsty/Research methods for students, aca	05/08/2011
Namuleme, Robinah Kalemeera	004496565	Medical Reference Services Quarterly / - Information n	20/12/2011
Namuleme, Robinah Kalemeera	004496565	European Journal of Personality / - Transactional theor	04/01/2012
Namuleme, Robinah Kalemeera	004496565	South African Journal of Libraries and Information Scien	12/01/2012
Namuleme, Robinah Kalemeera	004496565	Cancer Nursing / - Breast cancer patients' use of health	30/01/2012
Namuleme, Robinah Kalemeera	004496565	AIDS Care / - Seeking information about HIV/AIDS: a q	30/01/2012
Namuleme, Robinah Kalemeera	004496565	Human Communication Research III / - A Comprehensiv	13/02/2012
Namuleme, Robinah Kalemeera	004496565	Journal of Health Communication: International Perspec	11/04/2012
Namuleme, Robinah Kalemeera	004496565	Issues in mental health nursing / - Living with dying: cop	24/04/2012
Namuleme, Robinah Kalemeera	004496565	Health Psychology / - Coping and depressive symptom	24/04/2012
Namuleme, Robinah Kalemeera	004496565	Journal of Sexual Medicine / - Not supposed to touch: (24/04/2012
Namuleme, Robinah Kalemeera	004496565	Karen Glanz, Barbara K. Rimer./Health behavior and h	18/06/2012

Appendix A2: Sample Search Strategy

Search Journals Books My Workspace

Search History (11 searches) (Click to close)

View Saved

<input type="checkbox"/>	# ▲	Searches	Results	Search Type	Actions
<input type="checkbox"/>	1	Consumer Health Information/	1319	Advanced	Display More
<input type="checkbox"/>	2	seeking behavior.mp.	3413	Advanced	Display More
<input type="checkbox"/>	3	Health Knowledge, Attitudes, Practice/ or Health Education/ or Information Dissemination/ or Information Storage and Retrieval/	128663	Advanced	Display More
<input type="checkbox"/>	4	2 and 3	369	Advanced	Display More
<input type="checkbox"/>	5	Information seeking.mp.	1307	Advanced	Display More
<input type="checkbox"/>	6	4 and 5	173	Advanced	Display More
<input type="checkbox"/>	7	5 and 6	173	Advanced	Display More
<input type="checkbox"/>	8	Models, Theoretical/	92674	Advanced	Display More
<input type="checkbox"/>	9	model*.mp.	2140991	Advanced	Display More
<input type="checkbox"/>	10	8 or 9	2140991	Advanced	Display More
<input type="checkbox"/>	11	7 and 10	27	Advanced	Display More

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To search Open Access content on Ovid, go to Basic Ser

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Search Information

You searched: 7 and 10
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1. Health information-seeking behaviors among classically trained singers. Abstract Reference Complete Reference

Search Journals Books My Workspace

Search History (26 searches) (Click to close)

Map Term to Subject Heading

View Saved

<input type="checkbox"/>	# ▲	Searches	Results	Search Type	Actions
<input type="checkbox"/>	1	Consumer Health Information/	1319	Advanced	Display More
<input type="checkbox"/>	2	seeking behavior.mp.	3413	Advanced	Display More
<input type="checkbox"/>	3	Health Knowledge, Attitudes, Practice/ or Health Education/ or Information Dissemination/ or "Information Storage and Retrieval"/	128663	Advanced	Display More
<input type="checkbox"/>	4	2 and 3	369	Advanced	Display More
<input type="checkbox"/>	5	information seeking.mp.	1307	Advanced	Display More
<input type="checkbox"/>	6	4 and 5	173	Advanced	Display More
<input type="checkbox"/>	7	5 and 6	173	Advanced	Display More
<input type="checkbox"/>	8	Models, Theoretical/	92674	Advanced	Display More
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<input type="checkbox"/>	13	hiv.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	244372	Advanced	Display Delete More
<input type="checkbox"/>	14	12 or 13	244372	Advanced	Display More
<input type="checkbox"/>	15	Information behavior?.mp.	49	Advanced	Display More
<input type="checkbox"/>	16	Information Seeking Behavior/	321	Advanced	Display More
<input type="checkbox"/>	17	information seeking.mp.	1307	Advanced	Display More
<input type="checkbox"/>	18	information seeking behavior?.mp.	545	Advanced	Display More
<input type="checkbox"/>	19	Models, Educational/ or Models, Theoretical/	99683	Advanced	Display More

<input type="checkbox"/>	20	model*.mp.	2140991	Advanced	Display More >
<input type="checkbox"/>	21	15 or 16 or 17 or 18	1336	Advanced	Display More >
<input type="checkbox"/>	22	19 or 20	2140991	Advanced	Display More >
<input type="checkbox"/>	23	21 and 22	227	Advanced	Display More >
<input type="checkbox"/>	24	14 and 23	7	Advanced	Display More >
<input type="checkbox"/>	25	14 and 21	42	Advanced	Display More >
<input type="checkbox"/>	26	24 or 25	42	Advanced	Display More >

Combine selections with:

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 Author
 Title
 Journal

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<input type="button" value="Print"/> <input type="button" value="Email"/> <input type="button" value="Export"/> <input type="button" value="Add to My Projects"/> <input type="button" value="K Select"/>	
<input type="button" value="Clear Selected"/> View: Title Citation Abstract 10 Per Page <input type="text" value="1"/> <input type="button" value="GO"/>	
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You searched: 24 or 25 Search terms used: behavio?r hiv information information behavio?r information seeking information seeking behavio?r information seeking behavior model* models, educational models, theoretical seeking	
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Sort By: <input type="text" value=""/>	
Customize Display	
Filter By	
1. <input type="checkbox"/> Sexual health information seeking online: a mixed-methods study among lesbian, gay, bisexual, and transgender young people. Magee JC, Bigelow L, Dehaan S, Mustanski BS. <i>Health Education & Behavior</i> . 39(2):276-89, 2012 Jun. <i>[Journal Article. Research Support, Non-U.S. Gov't]</i> UI: 21490310 Authors Full Name Magee, Joshua C. Bigelow, Louisa, Dehaan, Samantha, Mustanski, Brian S. <input type="button" value="View Abstract"/>	<ul style="list-style-type: none"> <input type="button" value="Abstract Reference"/> <input type="button" value="Complete Reference"/> <input type="button" value="Find Similar"/> <input type="button" value="Find Citing Articles"/> <input type="button" value="Library Holdings"/> <input type="button" value="Send to"/>
2. <input type="checkbox"/> Use of dietary supplements among people living with HIV/AIDS is associated with vulnerability to medical misinformation on the internet. Kalichman SC, Cherry C, White D, Jones M, Kalichman MO, Detorio MA, Caliendo AM, Schnazi RF. <i>AIDS Research & Therapy [Electronic Resource]</i> . 9(1):1, 2012.	<ul style="list-style-type: none"> <input type="button" value="Abstract Reference"/> <input type="button" value="Complete Reference"/> <input type="button" value="Find Similar"/> <input type="button" value="Find Citing Articles"/>
<input type="button" value="My Projects"/> <input type="button" value="Annotate"/>	

Appendix B: Ethical approval

University of Sheffield Mail - revised research ethics applicat... Page 1 of 1



Robinah K Namuleme <r.k.namuleme@sheffield.ac.uk>

revised research ethics application - approved

2 messages

Val Gillet <V.Gillet@sheffield.ac.uk> 26 January 2010 09:22

To: R K Namuleme <R.K.Namuleme@sheffield.ac.uk>

Cc: n.ford@sheffield.ac.uk

Dear Robinah,

Thank you again for submitting your revised ethics application forms.

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that it has now been approved on ethics grounds, on the basis that you will adhere to the documents that you submitted.

If during the course of your project you need to deviate from the documents you submitted please inform me.

Written approval will be required for significant deviations from or significant changes to the approved documents.

You may now commence your research.

Thanks,

Val
Ethics Administrator

R K Namuleme <R.K.Namuleme@sheffield.ac.uk> 26 January 2010 14:04

To: Val Gillet <V.Gillet@sheffield.ac.uk>

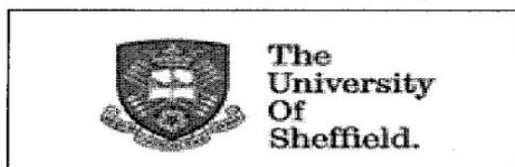
Dear Val,

Thanks for the feedback

RobinahQuoting Val Gillet <V.Gillet@sheffield.ac.uk>:
[Quoted text hidden]

<https://mail.google.com/mail/u/0/?ui=2&ik=4636d539b7&vi...> 05/09/2012

Appendix B1: Consent form



The University of Sheffield
Department of Information Studies,
Regent Court
211 Portobello Street
Sheffield S1 4DP

Participant Consent Form

Information and fighting HIV/AIDS: an Ethnographic study of Information behaviour

Name of Researcher: Robinah Kalemeera Namuleme

Participant Identification Number for this project:

Please the boxes below to indicate your consent to participate

1. I confirm that I have read and understand the information sheet dated February 2010 explaining the above research project and I have had the opportunity to ask questions about the project.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I can do so by simply contacting Mrs Robinah Kalemeera Namuleme at 07505041519
3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
4. I agree for the data collected from me to be used in future research
5. I agree to take part in the above research project.

Name of Participant Date Signature

Mrs R.K. Namuleme, Researcher Date Signature
To be signed and dated in presence of the participant

Copies:
Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Ethics Approval Date: 26.01.2010
Name of Researcher: Robinah Kalemeera Namuleme
Under Supervision of: Prof Nigel Ford

Appendix B2: Information sheet



The University of Sheffield
Department of Information Studies,
Regent Court
211 Portobello Street
Sheffield S1 4DP

Research information Sheet

Information and the fight against HIV/AIDS: An ethnographic study of information behaviour

Thank you for your interest in participating in this research project. Before you agree to participate it is important to understand why the research is being undertaken and what it will involve. The purpose of this information sheet is to help you to make an informed decision about taking part. The accuracy and objectivity of your response will have a significant impact on the research findings. Please take your time to decide if you wish to be involved in the research sample or not. Please contact me if there are any un-answered questions regarding the study after reading the information sheet.

In brief...

- This research seeks to understand what is happening in the daily lives of people directly or indirectly affected by HIV and AIDS in matters to do with accessing and using HIV and AIDS related **information** in mitigating the challenges posed by HIV and AIDS. This understanding will inform HIV and AIDS information management practitioners' efforts in the design, management and dissemination of information for the purpose of fighting HIV and AIDS. It requires one meeting
- Your participation is entirely voluntary and confidential
- The findings of this research project will be used in writing a PhD thesis.

Who can participate?

Participants in this study must meet any of the following criteria

1. Organisations which have close association with HIV/AIDS activities and information
2. Individuals affected by and/or with close association with HIV/AIDS activities and information, including vulnerable groups, persons living with HIV/AIDS, and persons caring for persons living with HIV/AIDS.

Any organisation, individual or groups of individuals meeting the above criteria will be considered but not necessarily recruited into the study.

5. Do I have to take part?

You are not compelled to participate in this research project. If you choose to participate you will be asked to sign a consent form. Likewise, you can withdraw at any time. Simply notify me using contact information provided on page 4.

What would participation involve?

This research tries to capture the world as you see it so there is no experiment involved. You just tell me about your “lived HIV and AIDS experiences”. This may involve your challenges, frustrations, and exciting experiences in living with HIV and AIDS.

You will need to sign a consent form indicating that you understand the nature of the research and agree to the terms of participation. The form may be sent to you ahead of time if you so wish, but otherwise shall be completed at the start of our meeting.

What will happen during our meeting?

We will start by reviewing the research project and giving you the opportunity to ask any questions you may have. Afterwards I will give you a piece of paper and request you to sketch out a picture indicating areas where information has been beneficial in your efforts to fight HIV and AIDS, and the sources that were useful to you.

In order to conduct my research I will, with your permission generate data through:

- informal conversation
- observations,
- open ended in-depth interviews,
- audio recording

You will be free to review any photographs that you authorise me to take before they will be used. I may need to contact you for further clarification after our meeting. The audio recordings and photographs will be kept securely, and will not be made available to anyone not directly involved in the research (including the researcher and supervisor). All data will be anonymous, and no one will be identified, or identifiable, in any report or publication arising from this research.

What do I have to do during our meeting?

If you agree to participate in the research project you will be asked engage in informal conversation, talk at length about your experience in accessing and using HIV and AIDS

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Under supervision of: Prof. Nigel Ford

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related information in the fight against AIDS. Answering the questions depend on your personal experience and your own knowledge. Please let me know at once if you are uncomfortable with the discussion so that we can take a break, skip a topic or reschedule the meeting.

What are the possible disadvantages and risks of taking part?

There should be no negative impact on individuals or HIV/AIDS based organisations taking part in this research. However, since this research deals with difficult issues such HIV/AIDS status, stigma and discrimination, some people may find that the interview becomes distressing. Please see the previous section for what to do if this is the case.

What are the possible benefits of taking part?

An immediate benefit to taking part is that each participant will receive £10 as compensation for their time. In broader terms my research aims gaining an understanding of the “lived information HIV and AIDS information experiences” in order to inform HIV and information management (including practices, strategies and policies). Hence this study seeks to contribute to the fight against HIV and AIDS by investigating the role of HIV/AIDS information management in enhancing the impact of HIV/AIDS-related information in the fight against HIV/AIDS. It is hoped that the research project will make a contribution towards HIV/AIDS information management which will enhance the impact of HIV/AIDS related information in the fight against HIV/AIDS

What happens if the research study stops earlier than expected?

If this research project stops earlier than expected, all data collected will be destroyed and participants will be informed of the reason for stopping earlier.

Will my taking part in this project be kept confidential?

Your assistance in providing required information is highly appreciated and valued. Please, be assured that all the information you provide will be kept with strict confidentiality and will be kept under lock and key at all times. Electronic files will be given passwords whenever possible. No one, except those closely involved in the research process (researcher and supervisor) will have access to the data. At the end of this research project, all transcripts of interview, the audio recording and photographs will be destroyed. In addition you will be referred to in all data, meetings and publications by an identification number or pseudonym.

What will happen to the results of the research project?

The data is being collected for a Doctor of Philosophy (PhD) degree. Findings of this research project will be used in writing a PhD thesis. Some of the collected data will be presented at conferences, and published in academic such as the *Journal of Documentation*, and the *Journal of Information Management*. No participants will be identified, or identifiable, in such presentations and publications, without their express permission.

Who is organising and funding the research?

This project is conducted under the rules and regulations governing post-graduate research at the University of Sheffield. It is being organised and funded by Nkumba University and me as a doctoral student.

Ethics Approval Date: 26.01.2010
Name of Researcher: Robinah Kalemeera Namuleme
Under supervision of: Prof. Nigel Ford

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HIV Act aware

Do you want to know?

- **What are HIV and AIDS?**
- **Who is at risk of contracting HIV?**
- **Why it is important to take an HIV test?**
- **Is there treatment for HIV?**
- **Where to get help.**

This information may be helpful to you.

HIV is one of the fastest growing serious health conditions in the UK. There are now more people living with HIV in the UK than ever before, over a quarter of whom do not know they have the virus.

Lack of knowledge about HIV among the general public in South Yorkshire has negative effects on the prevention and management of HIV and AIDS. Accurate and up-to-date information about HIV and AIDS can help to dispel unfounded fears, myths and stereotypes.

Where to get help

You can obtain information and social support from Shield, a South Yorkshire based local charity which offers holistic support to persons affected by HIV.

You can contact shield at:
(0114) 278 7916 or
www.shieldyorks.com



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Robinah K. Namuleme, PhD Research Student
 University of Sheffield
 Information School
 Regent Court
 211 Portobello Street
 Sheffield, S1 4DP



Thanks to the Roberts Fund Post Graduate Placement Scheme, University of Sheffield who funded the development of this leaflet.

What are HIV and AIDS?

HIV is a retro virus that attacks the immune system and makes it difficult for the body to fight off infections.

AIDS refers to the complications resulting from the damage caused by HIV to the immune system.

How is HIV transmitted?

HIV is mainly transmitted through unprotected sex, sharing needles, mother-to-baby and blood transfusion. However HIV, is not transmitted through sweat, tears, touch, saliva, insects or air.

Who can catch HIV?

There is a mistaken belief that HIV only affects gay men, black Africans and drug users. As a result, people from other ethnic backgrounds and sexual orientations think they are safe from HIV, hence the number of HIV infections has continued to rise within the general population.

Why it is important to take an HIV test?

When the HIV virus enters your body it may go unnoticed for up to 5–9 years.

The only way to know your HIV status is by taking an HIV test.

Testing is available free of charge on floor E of the Royal Hallamshire Hospital in Sheffield and/or your local GUM clinic. For further information or to book an appointment visit www.sth.nhs.uk or telephone **0114 276 6928**. The results of the test do not have to go on your medical record.

Is there treatment for HIV?

HIV is no longer seen as a 'death sentence' but rather a chronic manageable illness. Although there is no cure for HIV, with modern treatments HIV can be managed effectively and people diagnosed with HIV may live for many years.



HIV What you need to know

- **Newly diagnosed with HIV?**
- **No idea what HIV and AIDS are?**
- **Feeling very emotional about it?**
- **Worried about passing it on?**
- **Worried about the future?**
- **Unsure where to get information and social support?**

This information may help you.

Accurate and up-to-date information about HIV and AIDS can help to dispel unfounded fears that surround this disease and make living with HIV manageable.

Where to get help

You can obtain information and social support from Shield, a South Yorkshire based local charity which offers holistic support to persons affected by HIV.

You can contact shield at:
(0114) 278 7916 or
www.shieldsyorks.com



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Robinah K. Namuleme
PhD Research Student
University of Sheffield
Information School
Regent Court
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AIDS refers to the complications resulting from the damage caused by HIV to the immune system.

How is HIV transmitted?

HIV is mainly transmitted through unprotected sex, sharing needles, mother-to-baby and blood transfusion. However, HIV is not transmitted through sweat, tears, touch, saliva, insects or air.

Is there treatment for HIV?

HIV has moved on from being a 'death sentence' to a long-term manageable condition. Although there is no cure for HIV, with modern treatments HIV can be managed effectively and people diagnosed with HIV may live for many years.

Ways in which you can take care of yourself?

- Try to maintain a positive attitude by doing things you enjoy and trying not to worry too much.
- Try to live a healthy lifestyle by having a balanced diet, and not smoking and/or drinking excessively.
- Try to take life easy and have enough sleep every night.
- Find support and advice from HIV support agencies.
- Seek medical advice from health workers.
- Try to take your medications regularly as this can help to manage HIV.



Appendix D: The interview guide

The open-ended, in-depth exploratory interview guide:

At the start of every interview the researcher will:

- introduce herself, the project and the institution that is supervising the research project;
- give brief explanation about the nature of the interview and the research;
- assure prospective respondents of their confidentiality and explaining how privacy will be protected;
- inform interviewees that their views are very important to the research project and explain why;
- ask permission to record their views by audio recording and hand writing;
- make interviewees comfortable by asking how they are, how their day went and how their family is and any other appropriate small talk;
- ask the interviewee to sign the consent form.

A detailed description of how this will be done is given below

Explicit purpose

The researcher will offer an explanation about the interview to the prospective participants. She will attempt to be clear from the outset regarding the purpose of the interview.

The researcher will explain that reason she conducting this interview is to learn about your ‘lived HIV/AIDS-related information experiences’ especially, access to and use of HIV/AIDS related information in addressing the health, social and economic impact of HIV/AIDS I am interested in knowing your dilemmas, frustrations, and the factor/issues that enhance or impede your efforts in accessing and using HIV/AIDS information in the fight against HIV/AIDS”.

Project explanation

The researcher will explain to the prospective participants that information from their interview will be incorporated into a PhD project. She will tell them that this research will help her better understand factors that impede or enhance access and use HIV/AIDS related information. The researcher will take the information generated and study it to discover areas that need special attention as far as the design, organisation, and dissemination of HIV/AIDS related information is concerned.

Recording explanation.

From the outset of the interview the researcher will ask for permission to record the interview. She will explain that this would help her better to recall what they have said so that she can go over it letter and not to be tied to pen and paper during the interview.

The interview

Unlike the medical interview, where the medical doctor controls the interview, in this ethnographic interview, the participant to be the teacher. The researcher will keep a friendly conversational tone while keeping truck of the information being generated. The researcher will inform participants, that the current study seeking

to generate rich understanding of HIV/AIDS-related information experiences from their point of view. The researcher will encourage participants to talk about their information experiences the way you might to a family member or friend. The researcher will tell participants feel free because they were taking part in an informal conversation rather than formal interview.

To elicit information from informants, the researcher will be careful to ask questions in the same way each time so that responses could be compared.

Structure of the interview: Descriptive and experience questions

The interview questions for this study will be grouped into two broad categories/types. These include: descriptive questions, and critical incident and experience questions. A detailed description of the question categories is given below.

Descriptive questions

The descriptive questions intended to help the researcher to understand the experience of the participants. The researcher will ensure that the narrative is continued or sustained by using probes to elicit information from informants' perspectives

Some descriptive questions that the researcher employed in the current study are given below:

Would you please tell me about the information your information experience when you received the news of the HIV positive diagnosis?

Would you describe the kind of HIV/AIDS information you needed? (Probe= information needed not received, information avoided)

Could you say generally how useful or otherwise HIV/AIDS information you have come across? (Probe=something about the effectiveness of HIV/AIDS information- appropriateness)?

Critical incident and experience questions

Tell me of about instances you can remember when you needed HIV/AIDS information?

Can you tell me about the things/factors that enhanced or impeded your efforts in obtaining the information?

Can you describe your experience in accessing HIV/AIDS information?

Can you tell me your best experience s in accessing and using HIV/AIDS information (please list things that particularly made you happy)?

Can you tell me your worst experiences in trying to use and access HIV/AIDS Information (Please list things which were particularly annoying)?

What aspects of your life have been beneficially impacted by HIV/AIDS information? (This relates to any aspect of your life including medical, psychological, economic, social spiritual and economic aspects)

Has there been any information that you came across that was not beneficial /useful? If yes please tell me about it.

Is there information that you need that you need but has not been able to find?

Appendix E: Tables of HIV/AIDS-related information experiences

Table 3: Preliminary list of expressions describing the various responses to HIV/AIDS-related information

- I hide information;
- Cannot have HIV information in the house;
- Delete information;
- Bin information;
- Taught colleagues about HIV;
- Cannot read about HIV in the library;
- Cannot read about HIV in the bus;
- Stopped accessing information;
- Looked for information from the library;
- Do not read about HIV/AIDS;
- Reading about HIV plants a seed of fear;
- Looked for information from the internet;
- Asked friends ;
- Attended seminar;
- Went to a conference;
- Gave information ;
- Sent information;
- Taught them about HIV;
- Gave information to confront prejudice;
- Wrote my story;
- Go in schools to teach 13-16 year olds;
- My dad sent information to me;
- Learn about HIV as family;
- Taught my daughter;
- Spoke to colleagues who are positive;
- Read HIV updates;
- Hide HIV books under the bed;
- Shred HIV magazines after reading them;
- Brother doesn't want HIV books in his house;

- My brother tells me to throw HIV booklets away;
- I do not take information for myself.

Table 4: Preliminary list of expressions describing feelings experienced by PI/A
HIV/AIDS

- Shell shocked;
- World blown apart;
- World falling apart;
- Guilty;
- Ashamed;
- Embarrassed;
- Could not talk to my friends about it because even though I didn't know that much about it, I knew it was bad;
- Heartbroken;
- Heart wrenched;
- I thought I am dying soon;
- I had no hope for future;
- Head exploding;
- Felt quite alone;
- I looked with such a shock;
- It was really a big shock;
- I was upset;
- I was wild;
- I saw a black cloud;
- I am going to die'

- I thought that I was the only person that got it;
- Shock, thinking I am gonna die in three months;
- It was a real shock;
- It was in absolute shock;
- I was denying;
- I thought it was cancer not HIV;
- It couldn't be HIV;
- HIV could not cross my mind;
- I said...didn't ask for HIV;
- Could not take in information;
- I isolated myself;
- I felt alone;
- I can't mix in society;
- I lived in fear of other people finding out;
- Could not tell anyone;
- Concealed HIV status;
- My head exploding;
- Loss and grieving;
- My world fell apart;
- I was in Shock;
- It was denial;
- I came to terms;
- I developed fighting spirit.

Table 5: Preliminary list of expressions describing other people's perceptions and reactions to PI/A HIV/AIDS

- Dirty;
- Source of contagion;

- Dangerous;
- Grim Reaper;
- Slug;
- Prostitute;
- Made end of list;
- Put in isolation room;
- Sent away without treatment;
- Put on two sets of gloves ;
- Put big red sticker;
- Denied injections;
- Not treated with dignity;
- Disclosed my HIV status
- No right to confidentiality (Disclose positive status);
- Red sticker put on my file
- Gossip and rumour mongering
- Desertion;
- I didn't see her anymore;
- I was considered dangerous;
- Considered evil;
- Deviant;
- They thought I had no right to medical attention;
- Discloses my status before other patient;
- Treated like ghost;
- Throw stones at my window;
- Threw me out the house;
- Stopped their children from playing with my children;
- Binned all items I used in fear of contracting HIV.

Table 6: Preliminary list of perceptions about HIV/AIDS-related information.

- Information is over-scientific;
- I don't understand the medical jargon;
- It is too technical;
- It is above the common person's understanding;
- It is written for people with a good level of English
- HIV only comes out when it is associated with crime or asylum seekers;
- Information on TV is stigmatizing to those infected with HIV;
- It is too much;
- It is scary;
- It makes panicky;
- It plants a seed of fear;
- It is full of stereotypes of the 80s;
- It targets African and gay communities;
- It is over dramatised;
- It portrays HIV as a disease for Africans, gay people drug users and prostitutes;
- In lay man's language;
- Addresses myths about HIV;
- Stops isolation;
- Confronts prejudices and stigma;
- Creates awareness about HIV;
- Correct , reliable and up-to-date;
- Stops value judgments;
- Educates the public;
- Reduces ignorance, fear and stigma.

Table 7: Preliminary list of expressions describing where persons infected with or affected by HIV information obtained from

- Read library book;
- Got information from booklets;
- Watched documentary;
- Watched Eastenders;
- Watched news;
- Doctor at 'X' floor gave me information
- Got booklets from the clinic on 'X' floor
- Found information here (HIV support group);
- Only learnt about HIV when I came here (support group);
- People 's stories were my richest source of information;
- I rely on [Name] for information;
- Information comes through positive people;
- I attended a workshop;
- I went to a seminar;
- Seminars are brought in from London;
- I attended some conferences;
- People (face to face);
- I looked on the internet;
- I went on the internet;
- I subscribed to HIV online information;
- I get my information from websites such as NAM and THT;
- We sign post them to credible websites such as NAM, THT;
- I go on the internet to find new relationships;
- I went on internet to know about HIV.

Table 8: Preliminary list of expression of need for information

- Basic information about HIV;
- Meds;
- Side effects of meds;
- New drugs;
- Relationships;
- Social group;
- Dating;
- Friendships;
- Marriage;
- Mental health;
- Stress, anxiety and depression;
- Immigration;
- Where to get help;
- Care for self;
- Immigration;
- Jobs;
- Career;
- How to move on;
- Disclosure;
- Policies (future of medications, DDA);
- Negative emotions;
- Experiences of other people infected with HIV;
- Testing;
- Information on life after death.