Experiencing HIV and AIDS information: a phenomenological study of serodiscordant couples in Malawi

By:

Kondwani Dytone Wella

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

The University of Sheffield
Faculty of Social Sciences
Information School

August 2015

Abstract

There being no cure for HIV, information continues to play an important role in the management of the pandemic. However, the ability to design successful HIV and AIDS information campaigns is highly dependent on knowledge of people's information behaviour. Accordingly, there is a need for a clear understanding of the information behaviour of specific groups of people affected and infected by HIV. This phenomenological study investigates how serodiscordant couples experience HIV and AIDS information. In-depth interviews were conducted in the homes of twenty-one serodiscordant couples and three individuals who had separated from their partners. Participants for the study were selected purposively. Data analysis was done using Max Van Manen's phenomenological approach to generate descriptions and interpretations of the couples' experiences of HIV and AIDS information.

The findings of this study identify three major aspects of experiencing HIV and AIDS information. First, the life-world is the overarching context of experiencing HIV and AIDS information. The study identified five existentials of the life-world of serodiscordant couples. The four of the five existentials were similar to those described by Max Van Manen. These are: lived body, lived space, lived others, and lived time. In addition, my study identified spirituality as a fifth existential. The second aspect of experiencing HIV and AIDS information concerns the nature of HIV and AIDS information. Serodiscordant couples experienced information sources before experiencing the information itself. In these sources serodiscordant couples categorised HIV and AIDS information as being available or unavailable, and accessible or inaccessible. Thirdly, HIV and AIDS information was experienced with various emotional and cognitive states of mind. The emotions were categorised as positive, negative, and ambiguous. Furthermore, this study proposes a conceptual framework for experiencing HIV and AIDS information. The conceptual framework suggests that HIV and AIDS information was experienced while anticipating it, interacting with it, acting on it, and reflecting on it.

These findings reveal the complexity of experiencing HIV and AIDS information among serodiscordant couples. Recommendations are made for policy makers and practitioners on the importance of using knowledge of how serodiscordant couples experience HIV and AIDS information to design information services that suit their needs. In addition, this thesis highlights the need to have standard information materials for specific groups such as serodiscordant couples in order to effectively address their unique information needs.

Keywords: HIV, AIDS, serodiscordant couples, information experience, phenomenology, life-world, Malawi

Acronyms

ADC	Area Development Committee
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
CBO	Community Based Organisation
CD4 Count	CD4 cells are a type of white blood cells that play a major role in protecting our bodies from infection. CD4 count is a lab test that measures the number of CD4 cells in a sample of your blood.
COM	College of Medicine (University of Malawi)
COMREC	College of Medicine Research and Ethics Committee
COWLHA	Coalition of Women Living with HIV and AIDS
HIV	Human Immunodeficiency Virus
KCN	Kamuzu College of Nursing (University of Malawi)
LA	Artemether Lumefantrine
MANET	Malawi Network of People Living with HIV/AIDS
MBC	Malawi Broadcasting Corporation
MACRO	Malawi AIDS Counselling and Resource Organisation
MKW	Malawi Kwacha
NAC	National AIDS Commission
NAPHAM	National Association of People Living with HIV in Malawi
PLHIV	People Living with HIV
PMTCT	Prevention of Mothers to Child Transmission
UK	United Kingdom
UNDP	United Nations Development Programme

UNIMA	University of Malawi
USA	United States of America
TB	Tuberculosis
VCT	Voluntary Counselling and Testing
VDC	Village Development Committee
WHO	World Health Organisation
UNAIDS	Joint United Nations Programmes on HIV/AIDS

A glossary of selected Chichewa terms

Chichewa	A local language spoken by most Malawians
Chemwali	Sister
Malawi Kwacha	Currency of Malawi
Mdula moyo	Cutter of life
Tikuferanji	Literally means 'Why are we dying?' It is a name of TV soap aimed at educating people about social issues, including HIV and AIDS.
Timasukirane	Literally means 'let's open up to each other'. It is a name of TV soap aimed at breaking the silence about HIV and AIDS.
Zagwazatha	It has arrived and it's done. Usually said in reference to problems.

Acknowledgements

Special dedication

Table of contents

List of figures

List of tables

Chapter 1

Introduction

1.1   Introduction

This thesis reports on a study of HIV and AIDS information experience of serodiscordant couples in Malawi. Many married people in Africa are living in serodiscordant couples (World Health Organisation, 2014a). Besides, HIV still remains an important illness in the United Nations' post 2015 sustainable development goals (United Nations, 2015).

This chapter is divided into seven sections. The first section presents the context of the study. The section discusses the status of the HIV and AIDS pandemic in Africa and Malawi. The second section presents the statement of the problem this research investigated. In the third section, a statement of the problem this study addressed is presented followed by the research aim and objectives in section four. The fifth section outlines the reasons why this study is significant and worth conducting. In the sixth section I outline my personal encounter with HIV and this was part of a reflective process I undertook throughout the study. The chapter concludes with two sections; one outlining the project journey, and the other describing the outline of the rest of the thesis.

1.2   Research context

The study was conducted in Malawi. Malawi is a landlocked country in southeast Africa with Mozambique, Tanzania and Zambia as neighbours. With per capita Gross Domestic Product (GDP)of US$365.5 in 2011(The World Bank, 2013), Malawi is one of the poorest countries in the world. The country has a total area of approximately 118,484 square kilometres of which 24, 208 square kilometres is covered by Lake Malawi(National Statistical Office (NSO) and ICF Macro, 2011).

This research is about the experiencing of HIV and AIDS information by serodiscordant couples. World Health Organization (2012) defines a couple as two persons who are in a long term and continuing sexual relationship, and each person is referred to as a "partner". This study only focussed on heterosexual couples. A serodiscordant couple is a couple in which one partner is HIV-positive and the other is HIV-negative. This means that serodiscordant couples are made up of one person living with HIV and another person who is HIV negative. When both partners are HIV positive the couple is called seroconcordant positive (Bishop and Foreit, 2010). HIV

prevalence among couples is similar to that of the general population since the majority of adults of reproductive age are either married or in cohabiting relationships. World Health Organisation and Joint United Nations Programme on HIV/AIDS (2009) identified serodiscordant couples as a group where most of new infections were occurring but not included in HIV prevention programmes.

The study used a phenomenological approach. Phenomenology is a research approach that seeks to investigate the nature of the everyday world as we experience it, and not as we conceptualise it (Van Manen, 1997). A hermeneutic phenomenological approach developed by Max Van Manen for education research was adopted for the study.

1.2.1   HIV and AIDS in Malawi and Africa

Human Immunodeficiency Virus (HIV) is a virus that infects and impairs the function of the human immune system. This infection results in progressive deterioration of the immune system leading to a situation where it can no longer fight off infections and diseases (Joint United Nations Programme on HIV/AIDS, 2012a). On the other hand, Acquired Immunodeficiency Syndrome (AIDS) "is a surveillance definition based on signs, symptoms, infections, and cancers associated with the deficiency of the immune system that stems from infection with HIV" (Joint United Nations Programme on HIV/AIDS, 2012a)

At the end of 2013, the number of people living with HIV globally was estimated to be 35 million. Sub-Saharan Africa was home to 24.7 million (71%) of these people, making it a region that is most affected by the HIV pandemic. In 2012, 70% of all new adult and children HIV infections occurred in the Sub-Saharan region (Joint United Nations Programme on HIV/AIDS, 2013). Although, the number of HIV related deaths dropped by 39% in Sub-Saharan Africa, the region accounted for 74% of HIV related deaths world-wide (World Health Organisation, 2014b). With specific reference to couples and families Joint United Nations Programme on HIV/AIDS (2010) strategic plan for 2011 to 2015 aims to reduce HIV related maternal deaths, address HIV specific needs of women, and reduce gender based violence.

According to Malawi Government (2012a) the first HIV case was diagnosed in Malawi at Kamuzu Central Hospital in Lilongwe in 1985.The 2010 Malawi Demographic and Health Survey (MDHS) reported that 11% of adults aged 15-49 in Malawi are infected with HIV. The survey further indicated that in the same age group 13% of women and 8% of men were infected (National Statistical Office (NSO) and ICF Macro, 2011). When this is compared with the HIV prevalence of 2013 which was estimated to be 10.3% (World Health Organisation, 2015b) there are indications that the situation is improving. The downward trend of the HIV prevalence rate is shown in Figure

1.1 below. However, Squires (2012) argues that Malawi's HIV and AIDS programmes are too dependent on donors, hence not sustainable. In addition, in 2012, 80% of new HIV infections in Malawi were occurring among long term heterosexual serodiscordant couples (Malawi Government, 2012a) yet they are not included in many HIV prevention programmes (World Health Organisation and Joint United Nations Programme on HIV/AIDS, 2009).

Although the 2010 Malawi Demographic and Health Survey showed that there is universal awareness of HIV and AIDS in Malawi, several studies have indicated that this does not translate into behaviour change (Malawi Government, 2012a; Malawi National Aids Commission, 2007; National Statistical Office (NSO) and ICF Macro, 2011). Malawi Government further states that persons with higher educational qualifications in Malawi were the ones who were at higher risk of contracting HIV and yet they were the ones who were potentially more knowledgeable about HIV including how it is transmitted and prevented.
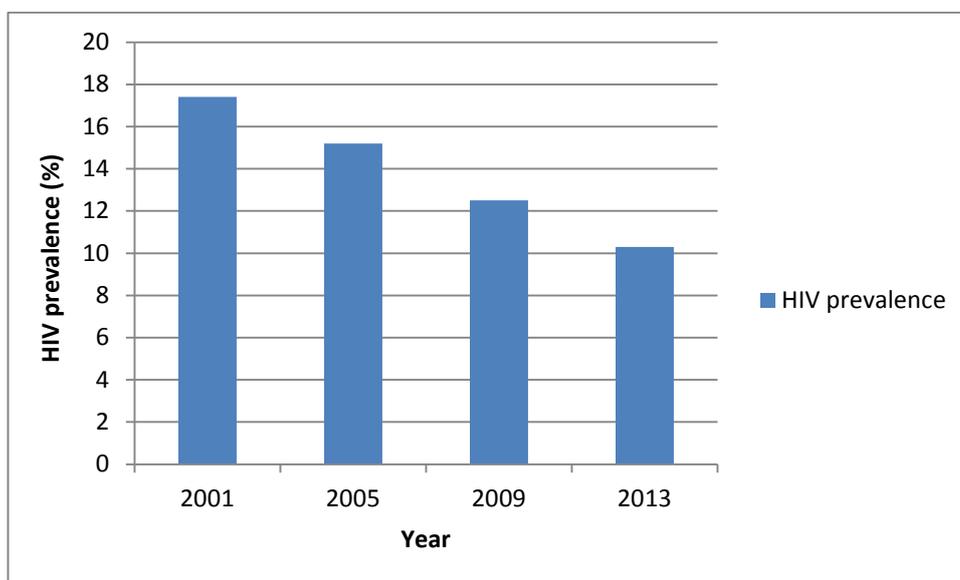
Figure 1.1: Malawi HIV prevalence. Data source: Global Health Observatory (World Health Organisation, 2015b)

According to 2008 results of the integrated household survey conducted in 2011, 85% of the population in Malawi resided in the rural areas (Malawi Government, 2012b) and depended on subsistence agriculture for their livelihood. This means that the impact of HIV and AIDS is felt the highest at family and community level in rural areas. In addition, people living with HIV (PLHIV), including serodiscordant couples face complex health situations while managing their illness and they require HIV and AIDS information in order to make good decisions. The HIV and AIDS pandemic has a negative impact on the socio-economic development of Malawi (Malawi Government, 2012a).

Discordance in long-term couples where protection is not being used came out as the second most important driver of HIV and AIDS in Malawi (Malawi Government, 2012a). This was also confirmed by the World Health Organization, Joint United Nations Programme on HIV/AIDS, and UNICEF (2011) in their 2011 progress report. Evidence from Uganda (Albright and Kawooya, 2005a, 2005b; Albright, Kawooya, and Hoff, 2007; Low-Beer and Stoneburner, 2003) suggests that effective HIV and AIDS information interventions have potential to change people's behaviour and reduce the spread of HIV. However, one of the important enablers of effective HIV interventions is understanding the information behaviour of people in general, and of people living with HIV in particular.

While there are many initiatives to provide HIV and AIDS information to PLHIV in Malawi there has not been consideration of the information behaviour of people living with HIV and AIDS. Albright (2007) contends that in the absence of a cure for HIV, information is the only weapon that, if used effectively, can assist to fight the HIV pandemic. To do this, Albright argues that we need to understand the context in which individual information behaviour takes place. Albright contends that understanding the context would assist in locating patterns of HIV and AIDS information seeking, accessing, using and avoiding.

1.3 Aim of study

The aim of this study is to describe and interpret how serodiscordant couples in Malawi experience HIV and AIDS information.

1.3.1 Specific objectives

1. Review previous research on information behaviour of HIV positive people and serodiscordant couples in particular
2. To identify information needs of serodiscordant couples in Malawi
3. To describe sources of HIV and AIDS information available to people serodiscordant couples in Malawi
4. To describe how serodiscordant couples' experience of HIV and AIDS information changed since their or spouse's serostatus changed
5. To describe how serodiscordant couples make sense of HIV and AIDS information
6. To make recommendations for changes in the approaches to HIV and AIDS communication

The research objectives are indicative of the phenomenological research approach that was used in this study. Phenomenology is a research approach that seeks to understand how people

experience a particular phenomenon in their life-world. The life-world is that region of reality in which human beings act out their lives and engage with themselves and others (Schutz and Luckmann, 1973). Further, phenomenology means describing things as they present themselves to consciousness (Ehrich, 1999). Van Manen (1997) posits that there are two types of description. First is the description of the lived experience, and second is description of the meaning of that experience. Thus Van Manen contends that the second type of description contains a stronger element of interpretation. Further, Schwandt (2007) argues that the two types of description differ in that one is concerned with events and actions (what), and often presented in the words of the research participants. The second type is focused on giving an account of how and why people do what they do. Therefore, the strength of a phenomenological description lies in the second type of description, which is interpretive. Besides, Van Manen (1997, p. 25) argues that "all description is ultimately interpretation".

1.4   Significance of the study

Although policy makers and practitioners in Malawi are aware that HIV information is an indispensable component of the fight against the HIV pandemic, their focus seems to be more on getting information to the people and not the information related dynamics that drive behaviour change.

According to the National AIDS Commission (Malawi) 80% of new HIV infections occur among serodiscordant couples. Therefore, understanding how they experience HIV and AIDS information is an essential prerequisite to success in the fight against the HIV pandemic. "Behavioral studies limit themselves to shedding light on the patterns of sexual practices among specific population and occupational groups. Often these studies merely highlight the cultural stereotypes of these specific groups ignoring the underlying circumstances for their behaviors" (Kalipeni and Ghosh, 2007).

This study is significant for four reasons. Firstly, HIV and AIDS have an impact on the development of Africa and the world. Therefore, it is important to develop knowledge on how to control its spread. In the absence of a cure for HIV, information is the only tool available that can be used to control the spread of HIV. Squires (2012) observes that Malawi has succeeded in managing the HIV pandemic by scaling up access to antiretroviral drugs which are donor dependent and unsustainable. This study investigates effective ways of using HIV and AIDS information to change people's behaviour. Secondly, to the best of my knowledge, there has not been any study on the HIV and AIDS related information behaviour conducted in Malawi. Internationally, Papadopoulou, Lee, and Fisher (2013) observe that information behaviour of

couples or people in dyadic relationships appear to be ignored in information science literature. Therefore, the proposed study will contribute to the understanding of the information behaviour of serodiscordant couples. In general the study will contribute to knowledge and understanding of information behaviour of people living with HIV. Thirdly, people living with HIV are marginalised. This study has the potential to give a voice to a group of people that is often not heard in the national discourse on HIV and AIDS. Fourthly, from the studies reviewed, phenomenology is not widely used to investigate information behaviour. Therefore this study will add to the body of literature of how phenomenology can be used in information behaviour research.

1.5   Motivation to do the study

The motivation to investigate information experience of serodiscordant couples arose from professional and personal encounters with HIV and AIDS. As an academic librarian in Malawi, I had always been aware of the contributions library and information services can make to national development. I had worked with nurses, medical doctors, and education professionals on HIV and AIDS projects which had information dissemination components. However, my role as a librarian was limited to supporting their work, like a midfielder in a game of football. While supporting these projects, I became aware of the 'disconnect' between information experience of the target audience and the intended outcomes of the projects.

Personally, I perceive information as an indispensable driver of national and global development agendas. In addition, I consider HIV and AIDS as a pandemic that can drive down all development efforts in Malawi. Malawi National Aids Commission (2012, p. 18) states that "because AIDS mainly affects economically productive people, the epidemic has had a major impact on the productivity of the public and private sectors- both rural and urban through prolonged absenteeism and death".

1.5.1   Personal encounter with HIV

In this study I wish to acknowledge myself as part of the setting and not detached. In phenomenology, researchers are encouraged to suspend their biases and assumptions about the phenomena. Schutz (1972) contends that it is only when we suspend the natural attitude[1] that we begin to see the constitution of the conscious experiences of phenomena. However, Ahern (1999) suggests that the aim of suspending biases and assumptions should be reflexivity and not to attain objectivity. In addition, Ahern argues that researchers should be aware of the biases and

---

[1]The natural attitude is the everyday attitude that takes the world as given. The concept is discussed in greater detail in Chapter 3 (section 3.5.1)

assumptions, and their effects of the research process, rather than trying to eliminate them. With this in mind I remained reflexive throughout this project and this will be discussed in detail in the course of the thesis.

I grew up in a rural village of the southern region of Malawi where, when I turned 12, I underwent traditional initiation as a rite of passage into adulthood. The initiation ceremony introduced me to the cultural values of my tribe. In addition, growing up in a family and village with deep cultural roots I learnt how to explain illnesses. I was also made to experience how the dead are treated and learn the burial rites. I learnt that some illnesses are caused by witchcraft and others are caused by natural forces like germs.

In 1998 I experienced terminal illness when my mother was diagnosed with breast cancer. The experience was traumatic because as a family we did not have access to information about the illness. It was only two weeks before her death that we were told about the diagnosis by the doctors. At the beginning of the illness we sought medical intervention from hospitals. Later we consulted traditional doctors. After everything had not worked we turned to religion.

My first encounter with HIV was in 2010 when my uncle, who at that time working in Johannesburg, was found HIV positive and later died. Around the same time two of my siblings also tested HIV positive and still live with the virus in seroconcordant couples. These close encounters with HIV were shocking for me. However, I still had questions about the nature of the experience for people living with HIV in Malawi, a country where access to health information is problematic.

As a librarian in a nursing college I learned the scientific truths about HIV and AIDS. This knowledge was acquired through supporting lecturers teaching courses and researching on HIV and AIDS. Further, as information professional I developed awareness of trusted sources of health information.

1.6   My project roadmap

1.6.1   Conceptualizing the study

I learned through personal life events and years of working as a librarian in the University of Malawi that information is important for patients and their carers when making decisions about their illness. Before starting the research project I conducted some background reading and I identified serodiscordant couples as group most vulnerable to being infected by HIV but not well covered by HIV and AIDS interventions.

The study commenced in October 2012 when I engaged in a review of literature on information behaviour of people living with HIV, especially serodiscordant couples. I also reviewed literature on information behaviour of people living with other disease conditions to fill gaps in HIV and AIDS literature. Through the review of literature I discovered that there was lack of studies on information behaviour of serodiscordant couples. In addition, the literature review revealed that although HIV and AIDS awareness was universal in Malawi, the knowledge was not translated into behaviour change.

1.6.2 Designing the study

Concurrent with literature review on information behaviour of people living with HIV, I considered different approaches to investigating the problem I had identified. I read about several research approaches and shortlisted three for careful scrutiny. The research approaches that were considered were phenomenology, ethnography and phenomenography.

The design process involved identification of the research approach, and data collection and analysis methods. In the design process I also considered the ethical appropriateness of my research design. Ethical approval for the study was obtained from the University of Sheffield, Information School Ethics Committee on 23 July 2013. In compliance with the requirements to conduct research in Malawi I had to seek another ethics approval from University of Malawi, College of Medicine Research and Ethics Committee which was granted on 13 September 2013.

1.6.3 Conducting the study

The data collection for the study was done in Malawi in September and October 2013. I started by piloting the interview guide with two serodiscordant couples. After modifying the interview guide based on the outcome of the pilot, I interviewed 21 serodiscordant couples and three individuals who were separated from their spouses because of serodiscordance. The fieldwork was a learning process as a researcher. In the course of the fieldwork I encountered some methodological and ethical issues that required me to make decisions.

Transcription of the data commenced concurrently with data collection. All data were transcribed by 19 December 2013. In my study, I approached the writing process as part of the analysis of data. Therefore, alongside analyzing the interview data using NVivo, I kept notes on issues that emerged from data. Although some chapters of my thesis were written in the early stages of my project, there was need to revise them in context of emerging literature and results from the analysis of data.

1.7   Outline of the thesis

The thesis is comprised of ten chapters. In this present chapter (chapter 1) the context of the research is discussed. In addition, it includes a general discussion of HIV and AIDS in Africa and Malawi. The first chapter also discusses the significance of the research. Chapter 2 reviews literature relevant to the study. The concept of information behaviour and other concepts associated with it are also discussed. The chapter concludes with a discussion of the implications of the literature on the study. Chapter 3 is a detailed discussion of the philosophical assumptions that guide social research. Phenomenology is discussed as a research approach that was used in the study. In Chapter 4, research methods that were used in the study are discussed. This includes a description of the population and how the study sample was determined.

Chapters 5, 6 and 7 present the results of the study. Chapter 5 focuses on the life-world as the context of experiencing HIV and AIDS information. In this chapter I present how the four existentials of the life-world arose from the descriptions of how serodiscordant couples experience HIV and AIDS information. The chapter concludes with the questioning of the fit of God and ancestral spirits into the 'lived others' existential. In chapter 6 I deal with two themes that relate to information needs, and HIV and AIDS information sources. Chapter 7 presents results on themes relating to experiencing HIV and AIDS information.

Chapter 8 consolidates the findings by describing and interpreting the descriptions of experiencing HIV and AIDS information by serodiscordant couples. Based on insights from previous studies I describe how serodiscordant couples experience HIV and AIDS information in four stages, namely experiencing HIV and AIDS information while anticipating it, experiencing HIV and AIDS information while interacting with it, experiencing HIV and AIDS information while acting on it, and experiencing HIV and AIDS information while reflecting on it. The description culminates into a framework of experiencing HIV and AIDS information.

In Chapter 9 I discuss the findings of my study in the context of the wider body of literature and previous studies. The thesis concludes with chapter 10. In this final chapter I begin by reflecting on the study research questions and how they have been answered. I also discuss limitations of the study, and contributions to theory, methods, practice, to Malawi context, and to the lives of the serodiscordant couples who participated in the study. The chapter concludes with recommendations for practice and future research.

Chapter 2

Literature review

2.1   Introduction

This chapter reviews literature on various aspects of information behaviour, HIV, serodiscordance, and HIV and AIDS information. I will first introduce the concepts of information and information behaviour. In addition to discussing information behaviour I will introduce the concept of information experience. I will then proceed by comparing two concepts that are important to my studies: life-world and small world. Then I will review literature on HIV and AIDS information, and living with HIV. The chapter concludes by discussing serodiscordance and HIV and AIDS information in Malawi.

2.2   Literature search methods

The literature review presented in this chapter was conducted in two phases. The first phase was conducted from October 2012 to July 2013 during the conceptualisation and design of this study. During this time I registered for table of contents alerts on journals relevant to my study, and followed discussion on relevant discussion lists in order to keep up-to-date with new literature on the subject of my thesis. This marked the commencement of the second phase of reviewing literature which finished in April 2015.

Library and information, and health/medicine databases were searched for articles on information behaviour, information experience, and living with HIV. More specific searches for information behaviour and serodiscordant couples were also conducted. Citation indices and reference lists of the articles were used for forward and backward chaining of relevant publications.

Research articles were searched in ProQuest, MEDLINE, Emerald and ScienceDirect using the following search terms; 'HIV/AIDS information', 'health information', 'health information practices', 'information behaviour', and 'people living with HIV'. The search terms were also combined using Boolean operators to form search queries. In MEDLINE the following MeSH terms were used "seropositive", "information seeking behaviour" and "consumer health information". Theses and dissertations were searched in Dart Europe E-theses Portal and ProQuest. Books were likewise searched in the University of Sheffield library catalogue and WorldCat.

Literature obtained from the search covered a wide range of topics and disciplines. In order to make the literature review process manageable I set some inclusion and exclusion criteria. The

review included studies on the information behaviour of people living with HIV in general, and on information behaviour of serodiscordant couples. Studies on behavioural interventions were only included if they focussed on HIV and AIDS information or messages as a driver of behaviour change. During the literature search, I discovered that not much had been published on the information behaviour of serodiscordant couples. Therefore, studies on information behaviour in relation to other illnesses were included. During the initial stages of reviewing literature very few publications on information experience were identified. In the course of the second stage of literature review some publications on information experience emerged, the highlight being the publication of a book titled; *Information Experience: Approaches to Theory and Practice.* Literature on biomedical and clinical interventions were excluded.

2.3   Information

Different authors have defined the concept "information" differently. Case (2012, p. 46) defined information as "whatever appears significant to a human being, whether originating from an external environment or a (psychologically) internal world". Parker (1974) as cited by Bates (2005 para. 17) says "*Information* is the pattern of organization of matter and energy".

Fox (1983) concedes that it is difficult to come up with a universal definition of information. Further, Fox states that that information is a phenomenon that all people recognise when they see it in its various forms. Wilson (2003) adds that information is not a simple phenomenon with a simple definition and viewed similarly among different professions. Thus, Wilson states that:

> "The computer scientist manipulates information; he or she manipulates units of complexity such as bits and bytes. The information retrieval specialist, on the other hand, conceives of information in terms of strings of symbols, matching query strings against indexed strings. The librarian sees information in terms of the macro containers; books, reports, journals and, now, electronic documents of various kinds, and, indeed of a higher level of organization, the library itself". (p.446)

Buckland (1991, p. 351) defines information based on the principal uses of the word "information". Buckland therefore define information in three ways; "information-as-process", "information-as-knowledge", and "information-as-thing". "Information-as-process" is where it refers to "the act of knowing" and "information as knowledge" refers to that which is perceived in "the act of knowing". Objects such as data and documents that are considered to be informative are also referred to as information.

In the context of this study 'information' is anything that has semantic content and aides knowing (Mathiesen, 2004). This definition of 'information' was considered broad enough to for investigation of HIV and AIDS information in Malawi, which predominantly has an oral culture (Albright, 2007). In chapters 7 and 9, I will revisit the definition of information in the context of serodiscordant couples' descriptions of HIV and AIDS information.

2.4   Information behaviour

The study of how serodiscordant couples experience HIV and AIDS information has a strong relation with information behaviour. Therefore it is important to discuss the concept of information behaviour and some theories associated with information behaviour. The discussion of information behaviour and information behaviour theories will guide the rest of the literature review.

Information behaviour is a well-established field of research in information science. This has been strengthened by the development of theoretical frameworks (Wilson, 2010). There is a growing body of literature that document the theories and models of information behaviour. Fisher, Erdelez, and McKechnie (2005) outline the most prominent theories and models of information behaviour in their monograph titled "Theories of Information Behaviour". In addition, Case (2012) in "Looking for Information: a survey of research on information seeking, needs, and behavior" gives a detailed introduction to the field of information behaviour.

To date, information behaviour has been identified as one of the major fields of research in librarianship and information science (Wilson, 2010). Over the years information behaviour research has shifted from a focus on systems, services and its users to investigating information seekers in their context (Wildemuth and Case, 2010). According to Case (2012), as one the major areas of research in information science, information behaviour will continue to grow and intersect with other disciplines. Wilson and Walsh (1996) state that information behaviour in relation to health problems has also been investigated by researchers in health disciplines, publishing the studies in their journals.

Information behaviour is defined by Wilson (2000, p. 49) as "the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use". Thus, it includes "face to-face communication with others, as well as the passive reception of information as in, for example, watching TV advertisements, without any intention to act on the information given". This definition is preferred because it comes from one of the most influential advocates of information behaviour (Savolainen, 2008). In addition, this

definition is used by many authors (Fisher et al., 2005; Pettigrew, Fidel, and Bruce, 2001; Savolainen, 2008). Commenting on Wilson (1999)'s definition, Savolainen (2008) states that information behaviour constitutes information seeking behaviour, information searching behaviour, and information use behaviour. Information behaviour also includes avoiding information which is not seeking information (Case, 2012) but a purposive behaviour displayed when people think they have the answer in their mind and they do not want it confirmed (Narayan, Case, and Edwards, 2011). Further, Pálsdóttir (2008) states that with the increasing number of sources and channels of information, relevance judgment is also an essential aspect of information behaviour. Therefore, when studying information behaviour, it is important to consider criteria that people use to evaluate the various sources of information and make their choices (Pálsdóttir, 2008).

2.4.1   Information avoidance

People are believed to actively seek information that is compatible with their worldview, internal state, beliefs and opinions. and avoid information that will make them uncomfortable (Narayan et al., 2011). However, Case (2012) contends that the assumption that the connection people make between information coming from external sources and their internal reality is without conflict is flawed. Although people know they have an information need, and know that access to information can be liberating, they can choose to avoid information because of feelings of fear, anxiety and other cognitive and emotional variables (Case, Andrews, Johnson, and Allard, 2005). Besides, the very act of avoiding information can be a strategy to cope with too much or unpleasant information (Johnson and Case, 2012).

Health information avoidance can happen in the process of information seeking or outside it. In a study of health information avoidance among university students Sairanen and Savolainen (2010) found that people avoid information comprehensively or selectively. In addition, the study found that people can start seeking information and stop the seeking process after encountering undesired information. The major reason for avoiding health information that came up in the study was the negative emotions that are associated with health information. Data for the study were collected using semi-structured interviews from a sample of nine students at Tampere University, Finland.

Studies have shown that there are two main types of information avoidance: passive avoidance and active avoidance (Namuleme, 2013; Narayan et al., 2011). As part of a bigger study of information behaviour Narayan et al. (2011) investigated information avoidance. The study conducted in USA, Australia, Canada, India, China, and Jordan recruited a sample of forty

participants who were asked to keep diaries of their information activities for two weeks. The results of the study indicate two types of information avoidance; passive avoidance, and active avoidance. In active avoidance people develop a habit of avoiding certain information such as on religion, political viewpoint or some worldview. On the other hand passive avoidance is short term behaviour where people avoid certain unsolicited information that comes their way. According to Narayan et al. such information tends to be on illness, relationships and finances. The study findings suggest that people avoid information when they think that paying attention to that information will cause conflict in their minds.

Namuleme (2013) used ethnographic approach to investigate the information behaviour of people living with HIV in the United Kingdom. The results were consistent with findings by Narayan et al. (2011). People living with HIV were found to avoid information because of feeling of stigma, and anxiety associated with HIV and AIDS. Namuleme's description of information avoidance among people living with HIV is consistent with active avoidance identified by Narayan et al. The study found that people living with HIV made up their mind to deliberately avoid information or places where information was provided.

2.4.2 Information seeking and use

Information seeking is an important aspect of information behaviour. Wilson (1981) identifies four types of information seeking behaviours: passive attention, passive search, active search, and ongoing search. In addition, Case (2012) observes that in our daily lives we constantly move between active and passive information seeking. According to Julien and Michels (2004) information seeking is caused by tangible or perceived circumstances that make a person aware of their information need. When those circumstances of pressing information need pass, people tend to return to the state of passive information seeking (Case, 2012).

An exploratory study conducted by Huber and Cruz (2000) in USA found that people living with HIV and AIDS actively seek information concerning their condition, health and well-being. Print and electronic survey questionnaires were administered to a convenience sample of HIV positive men and women in USA. The study found that female people living with HIV sought more information than their male counterparts. This was also confirmed in a qualitative case study conducted in Manicaland, Zimbabwe by Skovdal et al. (2011). The study used individual and group interviews to investigate factors that limit men's uptake of HIV and AIDS services. The results indicated that because masculinity means being brave, productive and sexually active men who were HIV positive lived in denial. As such, they avoided places where HIV and AIDS

were being discussed. In addition, seeking HIV and AIDS information was associated with being subservient which contradicts the male ego.

In a study conducted by Kutner, Steiner, Corbett, Jahnigen, and Barton (1999) in the USA people with terminal illnesses indicated that they needed as much information as possible about the disease they were suffering from. They also needed information about the treatment they were getting and other life sustaining therapies available. The study used qualitative interviews which were followed up with semi-structured interviews. All the participants in the study indicated that they preferred to consult health workers on all medical related issues of their illness.

Although people in Uganda also preferred to get health information from health professionals like those in Kutner et al. (1999), they faced some constraints that compromised information access and use. Musoke (2007) investigated the accessibility and use of health information by women in rural areas of Uganda. The study used a grounded theory approach with a purposive sample and semi-structured interviews. Musoke identified two types of constraints: constraints to information access, and constraints to information use. The major constraints to information access that were identified were economic constraints, social constraints, and personal constraints. The women identified lack of health workers in the areas where they lived as hindering access to health information.

Using Goffman's stigma management theory and Chatman's theory of information poverty Veinot (2009b) investigated the role of stigma in the establishment of personal HIV and AIDS information networks. According to Veinot, people control information they give to others about themselves in order to conceal their stigmatized agent. Through this process, people living with HIV create a network of people knowledgeable about their HIV status and on whom they rely for HIV and AIDS information. The study used semi-structured interviews with thirty-four people living with HIV and twenty-eight of the family members from rural regions of Canada. In addition, the study used health care and service providers as key informants. The results indicated that being diagnosed with HIV was a major change in the lives of the respondents, leading to significant adjustment in their relationship with others. In order to manage stigma, respondents made choices on what information to disclose or not. Disclosure of HIV status was a major decision in the lives of people living with HIV which determined the formation of HIV and AIDS information networks. Participants reported using self-protective strategies which reduced the sizes and number of information networks. These findings resonate with Namuleme's (2013) results where people living with HIV were hiding HIV and AIDS information because of fear of stigma. Namuleme

further reported that when HIV and AIDS information services concealed their identities by, for instance removing big banners, more people living with HIV were more comfortable to visit them.

2.4.3   Information encountering

One common aspect of human life is curiosity to learn more about something after encountering a bit of information about the subject (Case, 2012). Longo (2005) studied how one hundred twenty-one women diagnosed with breast cancer got health information they used to make health decisions. The majority of the women in the study got information passively while reading a magazine, listening to the radio, watching television or talking to a friend.

In addition to actively seeking information Erdelez (1999, 2005) contends that people can also find information unexpectedly. Erdelez (2005) groups information users based on their information encountering experiences into four categories. These are: "super-encounterers, encounterers, occasional encounterers, and non-encounterers " (p. 179). Erdelez (1999) states that super-encounterers are people who encounter information on a regular basis and consider information encountering as a major way of acquiring the information they need. Encounterers, on the other hand, often bump into information and enjoy the experience of encountering information. However, they do not consider information encountering as an important element of their information behaviour. The third category, occasional encounterers, is people who occasionally encounter information and only see these as lucky incidents. Lastly, non-encounterers are people who never recall encountering information.

Pálsdóttir (2010) investigated the connection between purposive health information seeking and information encountering among Icelanders. Survey questionnaires were used to collect two sets of data from a random sample of one thousand people aged between 18 and 80 years in 2002 and 2007. The analysis compared information encountering of the clusters of research participants based on their purposive information seeking behaviour. Clusters that were used are passive, moderately passive, moderately active, and active information seekers. The results of the study indicated that active information seekers were more likely to encounter information. Further, the study reported that people who were active information seekers were also active information encounterers. This agrees with Erdelez's (2005) model of information encountering. The model assumes that information seekers have general information need from which is divided into specific information needs on which active information seeking is based. The model further assumes that information encountering may occur within an information seeking task. During the information seeking episode the information user sees information potentially relevant

to the general information need, interrupts the original search, saves information encountered and deemed useful, and returns to the original search.

Foster and Ford (2003) investigated how inter-disciplinary researchers experienced serendipity in their information seeking. The study used interviews to collect data from a purposive sample drawn using snowball sampling from one hundred research groups in faculties of arts and humanities, social sciences, engineering and medicine. The study reported that serendipity was widely experienced among researchers and was described as "randomness", "chance", "accident". In addition, the study found that some information seekers believed that some control could be exercised to induce information encountering while others thought it was a manifestation of hidden controls instituted by information managers through classification.

2.4.4   Making sense of information

At a general level, sense-making is defined as the process through which people construct meaning of their world (Dervin, 1983). In the information searching process, the information seeker is driven by the need to fill a gap. Case (2012) contends that information search starts with questions in a person's mind directed towards a need to make sense of a situation at hand. HIV and AIDS information is a unique body of knowledge because of its complexity (Huber and Gillaspy, 1998). Huber and Gillaspy observe that HIV and AIDS information has three features. First, they posit that HIV and AIDS information is complex, second, it has diverse terminology to cater for the diverse audience of information producers and consumers, and lastly, the body of HIV and AIDS information is growing at an "epidemic rate" (pp. 191).

Bekalu and Eggermont (2013) investigated, using survey method, the differences between urban and rural people in the level of concern about HIV and AIDS, information needs, and types of HIV and AIDS related information needed. A random sample of nine hundred ninety-five participants (497 from rural, 498 from urban) between the ages of 15 to 34 was drawn from two towns and two villages in Ethiopia. The study reported that place of residence (urban versus rural) was an important factor for determining a person's information needs. In addition Bekalu and Eggermont reported that rural people were less concerned about HIV and AIDS and had less HIV and AIDS related information needs as compared to urban people. Further, urban versus rural residency was found to be associated with the type of information people needed. More rural than urban were concerned about accessing basic HIV and AIDS information such as "what HIV and AIDS are, symptoms of HIV, causes or risk factors leading to HIV transmission, and methods of HIV prevention" (Bekalu and Eggermont, 2013, p. 8). More urban than rural people needed care and support information such as "how and where to get HIV tests/diagnosis, treatment and care (how

to access antiretroviral drugs), prevention of Mother-To-Child-Transmission (how, where, when to access it), and opportunistic diseases (what they are, how to cope with)" (Bekalu and Eggermont, 2013, p. 8). In Bekalu and Eggermont's (2013) study urban and rural people have different information gaps. This was reflected in the types of information they need and the HIV and AIDS related issues they are concerned about.

2.4.5   Information behaviour theories

Theories are generalizations and principles developed about relationships among various phenomena with respect to practice in a particular field (Case, 2012; Fisher et al., 2005). There are several models and theories of information behaviour that have been published over the years (Belkin, 2005; Chatman, 1996, 1999; Ellis, 2005; Nahl, 2005; Wilson, 2005; Yakel, 2005). These theories have been used to study different aspects of information behaviour (Fisher et al., 2005).

Glanz, Rimer, and Viswanath (2008) describe four ways in which theories can be used in research. First, a researcher can identify the theories that are relevant to the research but none or few elements of that theory are used or tested. The second option is where a researcher specifies a theory and applies most of its constructs to the research. Thirdly, a researcher can specify a theory and explicitly measure and test elements of that theory. Lastly, elements of a theory are used to build a revised or expanded version of that theory.

For the purposes of this study three theories of information behaviour developed by Tom Wilson and Elfreda Chatman were identified as relevant to the study. These are Wilson's Model of Information Behaviour, Chatman's information poverty theory, and Chatman's Theory of Life in the Round. These theories were selected because of their resonance with the concept of the life-world. Burnett and Jaeger (2008) assert that life-world concerns the macro-level of the everyday world, and Chatman's small world concerns the micro-level. Wilson's (1996) model resonates with the life-world because of its focus on the context in which all information related activities take place.

The theories were used to broaden the conceptual grounding of the study. As stated by Glanz et al. (2008), the theories were used to identify information behaviour related concepts relevant to the study. Meyers, Fisher, and Marcoux (2009, p. 337) contend that "what may begin as a small world, especially for those starting from sociology, morphs quickly into an information world as we land squarely in the middle of all the emotional, social, political, physical, technical, and, yes, informational complexity when we consider phenomena through the lens of Chatman". Therefore, Chatman's theories were useful for gaining insights into the life-world of serodiscordant couples.

Furthermore, the theories were used in the interpretation and discussion of the findings of my study. In case of Wilson's (1996) model, this culminated into a version of the model (Figure 9.1) that included examples from my findings.

2.4.5.1   Wilson's Model of Information Behaviour

Wilson's Model of Information Behaviour was chosen because it is widely used in research and has been tested. For instance, Ford, Miller, and Moss (2003, 2005) tested the elements of the model in a study investigating the effect of human differences on web search strategy. As stated earlier, the model was also chosen because of its emphasis on context which makes it relevant to exploration of information experience. Cole (2012) argues that it is essential to study information behaviour within a sociological context.

T.D. Wilson developed his first Model of Information Behaviour in 1981. The aim was to outline areas that are covered by people's information seeking behaviours. The model suggests that people seek information as a result of realising an information need. The information user then consults formal and informal sources of information in order to satisfy the need (Wilson, 1999). Later in 1981 Wilson developed another model which suggested that in the process of information seeking the information seeker meets barriers. Bringing together research from other fields such as psychology, health communication, decision making and consumer research, Wilson developed another model in 1996. The 1996 model was developed based on the basic frameworks of the two 1981 models (Wilson, 2005). It included intervening variables which can support or prevent information seeking. In addition, the 1996 model had more types of information seeking, and incorporated some theories; stress/coping theory, risk reward theory, self-efficacy theory and social learning theory. The model is presented in Fig 1 below.
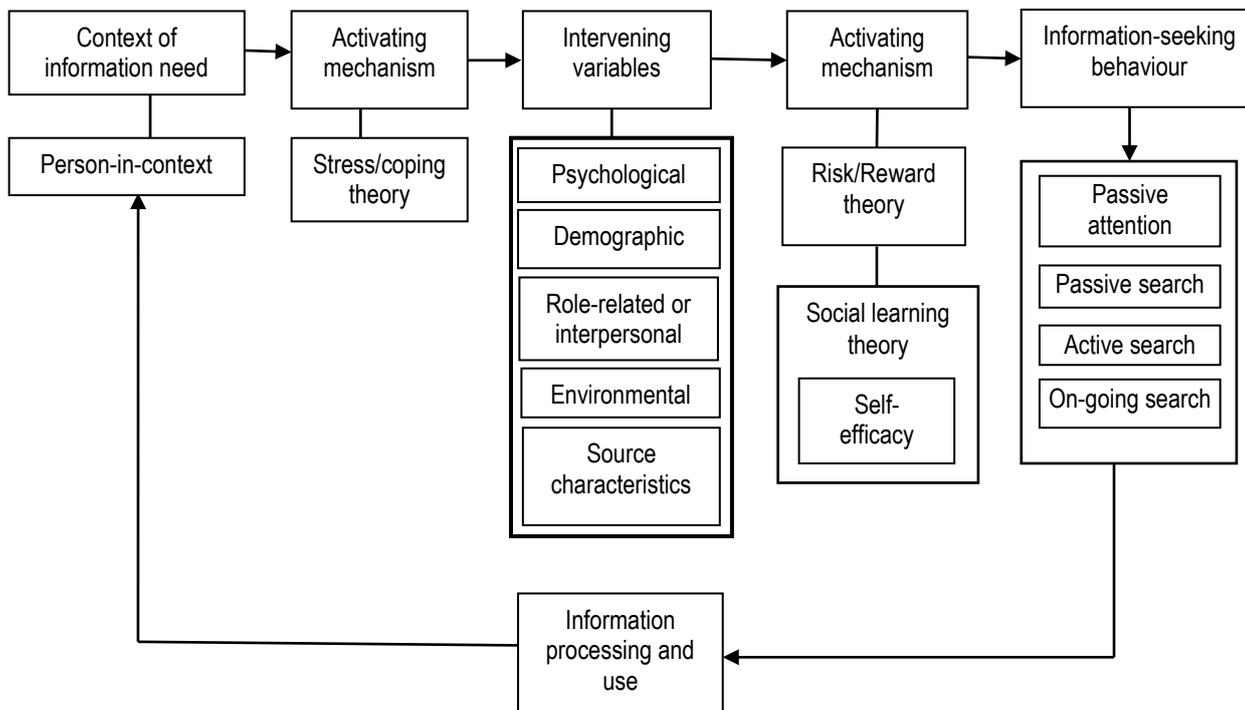
Figure 2.1: Wilson's (1996) Model of Information Behaviour. Reproduced with permission from publisher, from Wilson, T. D. (1999). Models in information behaviour research. *Journal of Documentation, 55*(3), 249-270.

The risk/reward theory is from consumer research and it was proposed by Settle and Alreck (1989). Wilson (1997) contends that when information search is undertaken one might be risking financial, psychological and physical resources. Social learning theory was influenced by ideas from the social stimulus theory and its fundamental concept is the self-efficacy theory (Wilson, 1997). The self-efficacy theory was proposed by Albert Bandura in psychology and "is based on the principal assumption that psychological procedures, whatever their form, serve as means of creating and strengthening expectations of personal efficacy" (Bandura, 1977, p. 193).

2.4.5.2   *Chatman's Theory of Information Poverty*

Elfreda Chatman's theory of information poverty was chosen because it has been widely used and tested in information behaviour research (Burnett and Jaeger, 2008; Hersberger, 2003; Lingel and Boyd, 2013). In addition, the four core concepts of the theory (secrecy, deception, risk-taking, and situational relevance) are relevant to HIV and AIDS information. As stated earlier, the theory was chosen because of its resonance with the life-world.

Although the development of this theory was influenced by several studies (Hersberger, 2005), Chatman's work with retired women was pivotal to its conceptualisation. Chatman (1992) observed and interviewed old women living in a retirement home

In the theory of information poverty Chatman (1996) draws a distinction between information insiders and outsiders of a particular life world. As described by Chatman, insiders share a common cultural, social and religious perspective by which their shared experiences are shaped.

On the other hand, those that do not belong to this community are viewed as outsiders. According to Merton (1972, p. 15) an "Outsider has neither been socialized in the group nor has engaged in the run of experience that makes up its life, and therefore cannot have the direct, intuitive sensitivity that alone makes empathic understanding possible".

The theory is based on five propositions, namely;

"Proposition 1

People who are defined as information poor perceive themselves to be devoid of any sources that might help them.

Proposition 2

Information poverty is partially associated with class distinction. That is, the condition of information poverty is influenced by outsiders who withhold privileged access to information.

Proposition 3

Information poverty is determined by self-protective behaviours which are used in response to social norms.

Proposition 4

Both secrecy and deception are self-protecting mechanisms due to a sense of mistrust regarding the interest or ability of others to provide useful information.

Proposition 5

A decision to risk exposure about our true problems is often not taken due to a perception that negative consequences outweigh benefits

New knowledge will be selectively introduced into the information world of poor people. A condition that influence this processes is the relevance of that information in response to everyday problems and concerns" (Chatman, 1996, pp. 197-198).

2.4.5.3   *Chatman's Theory of Life in the Round*

The Theory of Life in the Round is widely cited in literature (Case, 2012; Chiu and Eysenbach, 2011; Meyers et al., 2009; Savolainen, 2008). Besides, the theory is oriented towards exploring information behaviour in a social context (Fulton, 2005).

The Theory of Life in the Round arose from Chatman's research during the 1980s and 1990s (Fulton, 2005). In this theory, life in the round is defined as lived in a small world where there are a lot of uncertainties. Members of the small world are only concerned with their world, and information that can be used in there (Chatman, 1999; Fulton, 2005). Chatman, in her study of information behaviour of women in a maximum security prison noted that information facilitated the change in new inmates from being a prison outsider to a prison insider (Chatman, 1999). Information sharing sets boundaries within which one should play out one's life. Chatman also explains that women in prison suspend the reality that they experienced outside prison and adopt a new reality so that they are accepted. This is demonstrated in her description of how new inmates who were dependent on drugs and alcohol before coming to prison began to lose their dependence as they adjusted to prison life.

The Theory of Life in the Round is based on six propositions as follows;

"Proposition 1

A small world conceptualization is essential to a life in the round because it establishes legitimized others (primarily "insiders") within that world that set boundaries on behaviour.

Proposition 2

Social norms force private behaviour to undergo public scrutiny. It is this public arena that deems behaviour—including information-seeking behaviour—appropriate or not.

Proposition 3

The result of establishing appropriate behaviour is the creation of a worldview. This worldview includes language, values, meaning, symbols, and a context that holds the worldview within temporal boundaries.

Proposition 4

For most of us, a worldview is played out as life in the round. Fundamentally, this is a life taken for granted. It works most of the time with enough predictability that, unless a critical problem arises, there is no point in seeking information.

Proposition 5

Members who live in the round will not cross the boundaries of their world to seek information.

Proposition 6

Individuals will cross information boundaries only to the extent that the following conditions are met: (1) the information is perceived as critical, (2) there is a collective expectation that the information is relevant, and (3) a perception exists that the life lived in the round is no longer functioning" (Chatman, 1999, p. 214)

Four concepts stand out in the six propositions; "small world", "social norms", "worldview", and "social types". A small world is described by Chatman (1999) as a community where people are bound by customs, common language, and like mindedness. The concept of "small world" is not Chatman's creation. It had already been articulated by other sociologists such as Luckmann (1970). Based on the worldview and social norms, people in a small world have a shared awareness of what sources of information are acceptable, what sources are trustworthy and what sources are to be avoided (Chatman, 1999). Information from sources outside the small world is not valued and people may casually refer to it in discussions about the trustworthiness of its source (Pendleton and Chatman, 1998).

"Social norms are standards of acceptable behaviour in a given context" (Fulton, 2005, p. 80) and they form the basis for deciding the boundary between the small world and the larger world. Therefore any information coming from sources outside the small world that conflict with these social norms is rejected (Burnett, Jaeger, and Thompson, 2008).

Worldview consists of beliefs, customs, and language members of a small world share. These are used to interpret life in the small world (Fulton, 2005). When information does not fit in with the worldview of a small world it is considered of little importance and is safely ignored (Burnett et al., 2008). On the basis of a small world's worldview, "outsiders" are not trusted and information they provide is treated with suspicion (Pendleton and Chatman, 1998).

In a small world individuals are classified based on their way of behaving, conversing, and interacting with others; these are called social types (Burnett, Besant, and Chatman, 2001). Social typing occurs inside a small world, and on the boundary with the larger world where unfamiliar people are validated. Based on these social types, other people are trusted sources of information while others are not (Burnett and Jaeger, 2008).

Both theories are based on the conceptual framework of information insiders and outsiders. However, the two theories differ on the key concepts shaping them. The Theory of Information Poverty is based on "four key concepts: secrecy, deception, risk taking, and situational relevance, each of which may be invoked as self-protective behaviours during information seeking process"

(Hersberger, 2005, p. 76). On the other hand, central concepts for the Theory of Life in the Round are small world, social norms, social types and worldview.

The concept of 'small world' will be discussed further in the next section to compare it with that of 'life world'. These two concepts are essential to understanding the environment in which serodiscordant couples play out their lives.

2.4.6   Information experience

Information experience is an emerging concept within information science research (V. Reddy, 2014). It is understood as the holistic engagement with information within the life-world. Information experience is now being investigated in different contexts. Hepworth, Grunewald, and Walton (2014) distinguish information experience from information behaviour. They observe that information experience is internal, and personal interpretation of engagement with information while information behaviour external and observable.

Lloyd (2009) investigated the use and experience of information by ambulance officers in Australia. The study used a purposive sample of sixteen men and women and in-depth interviews. Lloyd found that ambulance officers experienced information through bodies of people at incident scene and of their patients. Ambulance officers reported that pulse rate, blood pressure, and temperature were important information they obtained from the patient's body. Lloyd's findings suggest that information sources can be the environment or the human body. These findings resonate with the lived body identified by Van Manen (1997) as one existential of the life-world. Van Manen argues that the lived body always reveals something, while concealing other details about the self. In another study Lloyd, Bonner, and Dawson-Rose (2013) contends that the life-world is a region of reality where communicative action takes place. The study used semi-structured interviews with a purposive sample of ten people living with chronic health condition, including HIV in Australia. In their findings Lloyd et al. suggested that the initial experience of the chronic illness is through the lived-body. In addition, the study found that the experience of health information was through three categories of information sources, "namely epistemic, social and corporeal sources" (p. 207).

Using two studies, Partridge and Yates (2014) explored information experience as a research object, and as a research domain. The first study, conducted in Queensland, Australia, investigated how people experienced information while using social media during a disaster. The study used grounded theory and collected data using semi-structured interviews from twenty-five people (Bunce, Partridge, and Davis, 2012). The other study used phenomenography to explore the different ways in which people experienced information during a disaster in Brisbane. This

second study used in-depth interviews to collect data from seven people who had been affected by the disaster (Yates and Partridge, 2014). The experience of conducting the two studies assisted Partridge and Yates (2014) to discover that what they were investigating was not information literacy but information experience. In addition, the exploration established that the two studies were in the research domain of information experience. Therefore, Partridge and Yates (2014) observe that information experience is an emerging domain in information science research.

2.4.7   Information behaviour research methodologies

This section discusses trends in methods that have been used to study information behaviour. Different commentators have described the changes and diversity in the approaches used in information behaviour research.

Wilson (2010) maps out the historical development of information behaviour research. I wish to particularly highlight two of the four time periods described by Wilson. The first is the period between 1959 and 1979 where information behaviour research was characterized by quantitative approaches. Some of the dominant data collection methods during this time period were questionnaires, interview schedules and diary forms. The second time period is from 1980 to 2009, the year he wrote the paper. Wilson observes that there was a shift to qualitative approaches in information behaviour research. Studies conducted in this time period were described as in-depth and using smaller samples.

This shift to qualitative approaches in information behaviour research is also observed by Ellis (2011). Ellis contends that the significance of this shift was the emergence of conceptual modelling in information behavior research taking place between late 1970s and early 1980s. Some of the research approaches mentioned by Ellis were grounded theory, ethnography and phenomenology. Ellis also identifies four important dimensions that characterized the emergence of conceptual thinking in information behavior research. These are adoption of social science perspective, use of qualitative approaches, a focus on modelling of information behaviour, and provision of empirical basis for models.

The diversity of contemporary information behaviour research is described by Case (2012). Case suggests that the most common research approach used in information behaviour research is survey. Data are collected using print and online questionnaires, or interviews. Other research approaches identified by Case (2012) include case study, phenomenology, laboratory experiments, field experiments, content analysis, and mixed methods.

According to Wilson (2003) information behaviour research needs to go beyond counting and seek to understand the meaning behind the actions of the information seeker. Wilson posits that we need to analyze what the information seek think is doing when searching for information, what intentions are embedded in their actions, and what meaning do they get from the information they find. To achieve this Wilson (2003) proposes the use of phenomenology.

2.4.8   Summary of information behaviour

The three theories reviewed in this section map out a landscape of an information world in which people play out their lives. Chatman (1999) describes a world defined by social norms, a shared worldview, and people belonging to social types. She calls this a "small world". Chatman contends that social norms and world view form the popular opinion that shapes people's actions in a small world. "It is a life in which certain things are implicitly understood" (Chatman, 1999, p. 212).

Wilson's Model of Information Behaviour is important to this study in two aspects. Firstly, it uses theories from other fields such as psychology, consumer research, and health communication to explain why some sources of information are used more than others. Secondly, the theory explains why other needs result in information seeking more than others (Case, 2012). In addition, Wilson (1999) asserts that during information seeking people encounter "intervening variables" that either influence or discourage the information seeker.

2.4.9   Reflection on information behaviour theories and models

The main objective of the study is to investigate how couples faced with a life threatening health condition; HIV and AIDS, experience HIV information. Two theories of information behaviour identified as being applicable to the study were Wilson's (1996) Model of Information Behaviour (Wilson, 1997; Wilson and Walsh, 1996), and Chatman's Theory of Life in the Round (Chatman, 1999).

In the Theory of Life in the Round Elfreda Chatman describes the relationship between information seeking and contextual factors such as social norms, social types and worldview (Savolainen, 2008). Chatman demonstrated that these factors influence or discourage people to seek, use or share information in a specific context. According to Chatman (1999) people naturally worry about things in their local environment, things that are tangible rather than those that are far away. Life in the round is lived in a community where there is shared and implicit meaning of things based on a shared worldview, and social norms. This creates a boundary creating a "small world" where people not sharing the worldview and social norms are considered

outsiders. In the sixth proposition in the Theory of Life in the Round Chatman (1999) called this an "information boundary".

One limitation of the Theory of Life in the Round is its focus on the small world as closed space of information activity. While in real life people interact with others occupying different social and physical spaces, Chatman's theory does not account for information sharing across small worlds. As noted by Burnett and Jaeger (2008) information is shared across small worlds using mass media such as radio, television and newspapers. In addition, people in small worlds participate in national discourse on important issues through which they also receive and share information.

The other theory identified as being relevant to this study, Wilson's (1996) Model of Information Behaviour covers a wider range of issues. The theory addresses other information seeking activities such as passive information seeking. "Passive search" in Wilson (1996) model opens up the possibility of information seeker receiving information sources that they have not actively pursued. It is evident that the assumptions Wilson (1981) made in the first version of his second model persist in the revised version of 1996. The assumption is that information needs are secondary needs, arising from other needs that are primary. In the model Wilson makes another assumption that in the process of seeking information people encounter variables that either prevent or support information seeking (Wilson, 1999).

On the other hand, Niedźwiedzka (2003) notes that Wilson's (1996) Model of Information Behaviour is limited to information seeking by individuals. Niedźwiedzka contends that the model does not address information seeking through mediators or using information technologies or collaboratively with others.

2.5   The life-world, and small world

The concept of life-world originated from philosophy and was introduced by Edmund Husserl (Moran, 2012). The life-world is the region of reality where human beings play out their lives and they are able to change it while they operate in it. Being an intersubjective realm of reality, the objects, events, as well as actions by other players, already in the life world can limit freedom of action (Schutz and Luckmann, 1973). The life-world is the lived world, the world we experience before we conceptualize and reflect on it (Van Manen, 1997). Van Manen further states that the life-world has four fundamental themes. These are "lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality)" (Van Manen, 1997, p. 101).

Lived space is that space we occupy at any particular time. Sitting in one's home gives a sense of security while walking alone on a busy street in a foreign land may render a sense of vulnerability (Van Manen, 1990). Benner (1994) describes things in a life-world as espoused by Heidegger as being either close or remote. Naturally, people are more concerned with things that are close or within reach (Schutz and Luckmann, 1973).

One important lived space for people living with HIV is the HIV and AIDS support group. Ramlagan, Peltzer, Phaswana-Mafuya, and Aquilera (2010) investigated the expectations people living with HIV had from HIV and AIDS support groups. A brief survey and focus group discussion were conducted with a purposive sample of thirty-four people living with HIV who were members of support groups in South Africa. Ramlagan et al. found that people living with HIV faced stigma at home and they expected the support group to be a safe place for them. In addition, the study found that members of support groups expected that if people who are only affected (not infected) by HIV join the support group, they should be required to maintain confidentiality.

Lived body refers to our existence in the world in bodily form. Bullington (2013) suggests that the lived body is ambiguous; physiological and psychological. Kneck, Klang, and Fagerberg (2011) demonstrated this in a study on how people learn to live with diabetes. The study conducted in a Swedish university hospital used interviews to get a selective sample of diabetes patients describe how they experienced living with diabetes. Results of the study suggest that patients experience physical and emotional signs which inform them about their bodies and the world around them. In addition, participants believed that their bodies were a basis for making important decisions.

Lived time is the subjective time, which slows down when we are bored or participating in some boring activity and speeds up when we are enjoying what we are doing (Van Manen, 1997). Zhou (2010) investigated how people living with HIV experienced lived time in China. The study used semi-structured in-depth interviews with a purposive sample of people living with HIV in order to describe how they experienced lived time. Zhou found that people living with HIV experienced lived time in three ways. First, lived time was experienced as linear progressing from past to present, and into the future. Secondly, lived time was experienced in relation to others, and lastly people living HIV experienced reconstructed lived time. Further, Zhou observes that the experience of lived time facilitated reorganization of daily routines, relationship with others, and preparation for the future.

Although the study conducted by Ezekiel, Talle, Juma, and Klepp (2009) was not on information experience, it demonstrates how experiencing of HIV and AIDS information affects the perception

of the lived body. The study investigated how local terms used to describe anti-retroviral therapy related to conceptions of the body, illness, and efficacy of the therapy in Tanzania. Ezekiel et al. conducted twenty-one focus-group discussions with one hundred ninety-three young people using a semi-structured focus group guide. The findings of the study revealed some confusion regarding calling anti-retroviral therapy treatment or drugs when there is no cure for HIV. In addition, the study suggests that the seemingly correct terminologies for HIV and AIDS, translated into the local language, had negative connotations about the body. When translated into the local language anti-retroviral therapy is 'life prolonging drug'. Other terms used in Tanzania were 'energy enhancing drugs', 'drugs to extend days', and 'fattening drugs'. All these terms were found to connote dead bodies whose lives are sustained by drugs.

Veinot (2010) study concerns the fourth existential of the life-world, lived others. The study investigated the extent to which rural people in Canada shared HIV and AIDS information with their peers, and whether they valued those networks. Veinot interviewed thirty-four people recruited from community based organization, and health facilities. The study found that many people living with HIV had well established information networks with other people living with HIV. In addition, Veinot reported that people living with HIV valued HIV and AIDS information obtained from others.

The concept of lived others resonates with that of social capital investigated by Gregson et al. (2011). The study, investigating the effect of social capital on HIV prevention, used census approach in Manicaland Province in Zimbabwe. The baseline census was conducted between 1998 and 2000, and two follow-up censuses were conducted between 2001 and 2003 and between 2003 and 2005. The study found that men and women tended to join different types of groups. Women were interested in rotating credit groups, burial societies, and cooperatives. On the other hand men joined sports and youth clubs. The study also found that participation in social groups resulted in adoption of safer sexual behaviours among women.

Now I will discuss the concept of small world as espoused by Elfreda Chatman. As stated earlier, central to Chatman's theories are the concepts of insiders and outsiders. These are concept is based on the notion of "small worlds" which was described by Elfreda Chatman when she studied how people constrained in small scale social environments used or did not use information (Burnett and Jaeger, 2008). As noted in section 2.4.5.3 the concept of small world was first described by other sociologists such as Luckmann (1970).

Chatman (1991) notes that small worlds of low income people are characterised by strong family and kin ties that define appropriate behaviour. This according to Chatman is established early in

life through elders and peers through socialization linked to awareness of the neighbourhood, talking to peers and friends. Small world is thus defined as social environment where people live bound geographically, culturally and by social economic status, where everyday life is characterised by commonness and routine, and occurrences are predictable (Burnett et al., 2008). Further Pendleton and Chatman (1998) state that a small world is only meaningful in its context. They recommend that discussion about a small world should be done in their context. Therefore, Chatman's work is useful in understanding how a piece of information can change its meaning in different small words (Burnett et al., 2008).

Information in a small world is shaped by the context and social norms which define what is acceptable behaviour (Pendleton and Chatman, 1998). In addition, sources of information are also viewed as either acceptable or unacceptable based on social norms or the social type of the person providing the information (Burnett et al., 2001). People in a small world support each other and engage in behaviour to protect themselves from outsiders (Chatman, 1999). According to Hersberger (2005) these protective behaviours affect the information seekers' access to useful information.

Elfreda Chatman's theories, Information Poverty and Life in the Round were jointly applied in the study of information world of HIV positive gay men in UK by (Minion, 2010). Minion states that people living with HIV are a socially identifiable group with the capacity to develop collective characteristics and shared codes of practice. He further points out that because of alienation and stigma people living with HIV would come to rely on each other on HIV and AIDS information than on outsiders.

Burnett and Jaeger (2008) observes that the life-world represents the wider world, while Chatman's small-worlds are the specific contexts. It is the context that enables members of a small-world to conduct their affairs in a routine and predictable manner (Burnett et al., 2001). In addition, Savolainen (2008) contends that information seeking in small world is guided by widely shared norms and beliefs. Similar to Chatman's description of small world, Savolainen contends that life in a life-world is taken for granted and people always think things will go on as they had been.

The two concepts, small world and life-world are useful for analysing information behaviour in social contexts (Burnett and Jaeger, 2011). However, Burnett and Jaeger argue that each of these concepts has limitations, making them problematic when used in isolation. Chatman's orienting concept of 'small world' is important as a lens through which to see into the life-world. Lived spaces such as the home and workplace are the primary zone of the life-world in which

everyday affairs take place (Schutz and Luckman, 1973). Chatman (1999) calls this primary zone of the life-world the 'small world' and provides a detailed synthesis of events and activities of people. Therefore, Chatman's theories provide effective tools for in-depth analysis of lived spaces in a specific life-world. On the other hand, the life-world makes possible the analysis of information behaviour beyond the small world, reaching across a broad array of culture (Burnett and Jaeger, 2011).

2.5.1   Summary for section 2.5

Literature reviewed in this section suggests that the life-world is taken for granted. As stated by Schutz and Luckmann (1973), we found it when we were born and we always assume it existed before. However, when circumstances change we become conscious of the life-world. For instance, we feel lost when walking on a busy street in a foreign country (Van Manen, 1997).

Studies reviewed in this section also identify the life-world as an important concept for people living with HIV. People living with HIV appear to experience stigma in some lived spaces as compared to others. As such, spaces such as HIV and AIDS support groups are considered to be safe (Ramlagan et al., 2010). In addition, people living with HIV appear to experience the life-world differently from others. For instance, lived time is experienced as truncated (Zhou, 2010), and the lived body is viewed as being supported by anti-retroviral drugs, which are called life prolonging (Ezekiel et al., 2009).

The discussion on the concept of the life-world presented in this section resonates with that of the small world. Similar to the life-world, life in a small world is described as routine and predictable (Pendleton and Chatman, 1998). Chatman (1999) describes the small world as being inhabited by people that are categorised into social types. In addition, social norms and a shared worldview define what acceptable behaviour is.

These two concepts are important to the study of information experience of serodiscordant couples because as stated by Van Manen (1997), although we always think it pre-existed us, we continually participate in creating it. Van Manen adds that investigation of human beings' experiences of phenomena is actually exploration of the structures of the life-world. Further, norms, and worldview of a small word shapes one's information behaviour and experience of information (Jaeger and Thompson, 2004).

2.6   HIV and AIDS information

Selected studies on HIV and AIDS have been reviewed in the preceding sections of the present chapter. In this section I will focus on effectiveness of HIV and AIDS information in the

management of the HIV pandemic. Literature reviewed in this section flag up attributes of successful and unsuccessful HIV and AIDS information campaigns.

People living with HIV need HIV and AIDS information for various reasons. They require information on causes and symptoms of HIV (Selman et al., 2009), medication information (Edewor, 2010; Huber and Cruz, 2000), treatment information (Huber and Cruz, 2000; Selman et al., 2009) wellness information (Edewor, 2010; Huber and Cruz, 2000), HIV and AIDS disclosure, dating and relationships, legal information (Huber and Cruz, 2000), and information on progression and management of HIV and AIDS (Selman et al., 2009). HIV and AIDS information has been used in the management of the HIV pandemic around the world. Studies have shown factors that have led to the success and failure of HIV and AIDS information campaigns.

Uganda reduced its HIV prevalence from 30% in 1992 to 8.3% in 1999 (Uganda National AIDS Commission, 2001) and studies conducted in the country have reported that effective dissemination of HIV and AIDS contributed to reduction of HIV prevalence rate (Albright and Kawooya, 2005a, 2005b; Low-Beer and Stoneburner, 2003). Low-Beer and Stoneburner (2003) identified unique features of the Ugandan HIV and AIDS information campaign that are thought to have contributed to its success. Low-Beer and Stoneburner observe that instead of broadcasting the information into the communities using mass media, Uganda adopted community led approaches. The approaches used integrated the cultural contexts of specific communities in the information.

The other feature associated with effective HIV and AIDS information campaigns in Uganda is the multi-sectoral approach of the programmes (Albright and Kawooya, 2005a, 2005b; Low-Beer and Stoneburner, 2003). Albright and Kawooya (2005b) used semi-structured interviews to investigate the kinds of HIV and AIDS information people received, specific sources from which they received information, the period over which they received the information and the media they got the information from. The results of the study indicated that three categories of HIV and AIDS information were disseminated. These were general information about HIV and AIDS, preventive information; and information that emphasized "the responsibility of all in society to care for people with AIDS without blame or passing judgment" (Albright and Kawooya, 2005b, p. 107). Albright and Kawooya state that information provision was successful because of the use of socially and culturally sensitive channels of communication, in addition to the formal HIV and AIDS networks.

In another study Albright and Kawooya (2005a) used case study approach to delve into reasons for the success of information HIV and AIDS provision in Uganda. Results of case studies of two organisations that provided HIV and AIDS information to people confirmed that a combination of

informal and formal channels were used to transmit information to target populations. These results agreed with those of Low-Beer and Stoneburner (2003) where they reported that although Uganda's HIV and AIDS knowledge indicators were similar for other countries, the country had unique HIV and AIDS communication strategies. Low-Beer and Stoneburner reviewed HIV and AIDS intervention strategies in Uganda in comparison to other countries such as Kenya, Malawi, Tanzania, Zambia, and Zimbabwe. The review showed that that communication about HIV and AIDS in Uganda used personal and social networks, while other countries used mass media.

The effectiveness of multi-sectoral approach to dissemination of HIV and AIDS information is corroborated by Muchini et al. (2011) in Zimbabwe. Muchini et al. (2011) report that HIV information programmes contributed to behaviour change in Zimbabwe. Muchini et al. used focused group discussions with two hundred men and women, and informant interviews to investigate people's perceptions of the causes of behaviour change in Zimbabwe. Among the reasons given for the change of behaviour were transmission of HIV and AIDS messages using interpesonal means and cultural sensitive programming. Participants in Muchini's study described the effectiveness of the collaboration among different players in HIV and AIDS programming. Among the important players that were identified in the study were musicians, religious organisations, government agencies, and community based organisations.

As reported in studies by Albright and Kawooya (2005a, 2005b); Low-Beer and Stoneburner (2003) and Muchini et al. (2011) one of the problems that leads to HIV and AIDS information not resulting in behaviour change is lack of participatory approaches in the dissemination of information. In many cases information providers come with pre-scripted HIV and AIDS information which in most cases turns out to be irrelevant . Studies conducted in Tanzania and Zimbabwe identified cases where HIV and AIDS information interventions failed because of lack of collaboration among different organisations working on similar initiatives (Manda, 2007; Uwah and Wright, 2012).

Manda (2007) investigated the reasons why information provision was not translated into behaviour change in Babati District. Using a purposive sample of one hundred thirty-one respondents, Manda conducted face to face interviews, focus group discussions and in-depth interviews with key informants. The results of the study showed that HIV and AIDS information did not result into behaviour change because of lack of participatory approaches in the dissemination of information. The study also highlighted the effect of cultural and normative values on the effectiveness of HIV and AIDS to influence behaviour change. Specifically, the

study reported that certain dominant cultural practices and norms influenced sexual and gender relationships more than HIV and AIDS information.

Knowledge about HIV and AIDS is important as it is a determinant of health seeking behaviour. Audet et al. (2012) investigated the levels of HIV and AIDS knowledge and health seeking behaviour of people living with HIV in Mozambique. The study used a cross-sectional design to interview a systematic sample of three hundred forty-nine adults. The study found that although people were aware of HIV and AIDS, their knowledge was limited to the sexual transmission of the virus and the condoms use. Audet et al. reported that most people interviewed in their study visited the hospital first and went to a traditional doctor when not getting better. In addition, the study found that people who knew that HIV had no cure were more likely to visit traditional doctors.

Ayenew, Leykun, Colebunders, and Deribew (2010) found that knowledge about HIV and AIDS, and the benefits of voluntary testing and counselling was a predictor of acceptance of HIV testing among people with tuberculosis (TB) in Ethiopia. The study interviewed two hundred eighty-two TB patients randomly selected from eight randomly selected TB clinics. In-depth interviews were also conducted with five nurse counsellors and fifteen TB patients. Ayenew et al. recommended that TB patients and the general public should be made aware of the association between TB and HIV, and the benefits HIV testing in order to increase the acceptability of Voluntary Counseling and Testing (VCT) services.

The literature reviewed in this section suggests that HIV and AIDS information has the potential to influence behavior change. There are features identified as being characteristic of successful HIV and AIDS information campaigns. Albright and Kawooya (2005a, 2005b); Low-Beer and Stoneburner (2003) and Muchini et al. (2011) observe that successful HIV and AIDS information campaigns in Africa used a multi-sectoral approach, and were sensitive to the cultures of the target populations. Some literature has also identified some features of HIV and AIDS information that worked against the intended outcomes of information campaigns. These include use of lack of collaboration among information providers, lack of participatory approaches, and information that is not responsive to the needs and cultures of the target populations.

2.6.1   Serodiscordance in HIV and AIDS information

According to World Health Organization (2012) couples can remain serodiscordant indefinitely if they consistently use condoms. Therefore, World Health Organisation and Joint United National Programme for HIV and AIDS encouraged national governments to scale up couple testing and counselling programmes (World Health Organization, 2012).

Serodiscordance is a phenomenon that is poorly understood (World Health Organization, 2012) and insights into the dynamics of serodiscordant relationships are also limited (Persson, 2013). Bunnell et al. (2005) in their study exploring serodiscordant couples' knowledge and explanations about serodiscordance found that there was lack of correct knowledge about their condition. The study conducted in Uganda recruited a purposive sample of serodiscordant couples attending a VCT clinic, and used in-depth interviews and focus group discussion to collect descriptions of their knowledge about serodiscordance. The study found that overall very few couples were able to state why serodiscordance exists. Bunnell et al. observe that this lack of knowledge about serodiscordance can lead to serodiscordant couples believing myths and misconceptions.

Lack of information about serodiscordance can also cause marriages to break up. In fact some couples do not go for HIV testing together for fear the repercussions if they have different HIV statuses (Mwale, 2014). Mwale investigated determinants for going for voluntary counselling and testing among women in Malawi. Focus group discussions were used to collect data from the women. The results showed that women avoided asking their husbands to go for HIV testing for fear of how they would react, and that they would assume the wife was unfaithful. Other women feared serodiscordant result would break up their marriage. However, a study conducted by Grinstead, Gregorich, Choi, and Coates (2001) in Kenya and Trinidad found that couples that went through professional counselling did not break up. The study only reported negative events among serodiscordant couples where the female partner was HIV positive.

In a study of sexual life and fertility desire of serodiscordant couples in Addis Ababa, Ethiopia Hailemariam, Kassie, and Sisay (2012) noted that for serodiscordant couples, knowing their serostatus was a beginning of a new experience. The study used grounded theory and in-depth interviews with a purposive sample of people in serodiscordant relationships and health professionals working in HIV clinics. The study reported that couples were faced with the struggle to save their relationship, deal with mismatch in desires for sex and to have children, and deal with issues of disclosure of their serostatus. While the couples were going through this process, they were faced with intervening conditions. These included pressure from relatives, information provided by HIV and AIDS management centres, and people's judgement.

Consistent with Hailemariam et al.'s (2012) findings, S. Allen et al. (2003) found that serodiscordant couples did not adhere to condom use after voluntary counselling and testing (VCT). The study conducted in Zambia, recruited nine hundred sixty-three heterosexual serodiscordant cohabiting couples identified through an HIV VCT centre. The couples' sexual history and demographic data were documented at the time of recruitment, and they were given

diaries to record condom use during sexual intercourse. At 3-monthly intervals the couples were tested for pregnancy and for evidence of unprotected sex. The results indicated that there was underreporting as 50% of vaginal smears had sperms and 32% of the couples tested positive for pregnancy when couples had reported using condoms.

In another study, Beyeza-Kashesya et al. (2010) reported that information provided by health care providers did not influence serodiscordant couples' reproductive decisions. One hundred and fourteen mutually disclosed serodiscordant couples receiving HIV care in four centres in Uganda were surveyed to determine factors that influenced the couples' reproductive decisions. Couples were found to be greatly influenced by relatives to have children. In addition, a member of a couple desired to have children when they knew their partner's desire to have children. Beyeza-Kashesya et al. (2010) findings resonate with those from Ngure et al.'s (2012) study. The study investigated the barriers to consistent condom use among serodiscordant couples in Kenya. Twenty-eight in-depth interviews and nine focus group discussions were conducted with purposively selected serodiscordant couples. The results revealed that despite undergoing counselling, male partners in serodiscordant couples were reluctant to use condoms.

Although S. Allen et al. (2003) and Beyeza-Kashesya et al. (2010) make no reference to information behaviour in the interpretation of their findings, the actions of the serodiscordant couples in the two studies point to information avoidance. Referring to Wilson's Model of Information Behaviour, Case et al. (2005) state that people's motivation to seek information is affected by intervening variables. The serodiscordant couples in S. Allen et al. (2003) and Beyeza-Kashesya et al.'s (2010) studies had their motivation to seek information affected by their relatives' and society's expectations. Their relatives and society expected them to have children as husband and wife so they avoided information that contradicted these expectations.

2.6.2   Perceptions of HIV and AIDS information

HIV is a disease that is characterized by fear of death, and of other people's reactions (Minion, 2010; Namuleme, 2013). Therefore, HIV and AIDS information is viewed with different perceptions. HIV and AIDS information is viewed as being disconnected from the realities of living with HIV. Namuleme found that most HIV and AIDS information materials found in the United Kingdom portrayed HIV as a disease of Africans and immigrants. In addition, HIV and AIDS messages were viewed as blaming people that are infected that it is their fault.

HIV messages in Tanzania were viewed by some youths in Tanzania to be educative, relevant, and evoking strong emotional feelings towards HIV and AIDS. On the other hand, other youths

thought the messages instilled fear and anxiety in people (Bastien, 2011). In the study, Bastien used focused group discussions with youths to investigate their perception of the use of fear in HIV and AIDS messages to influence change of behaviour. Overall, the youths were not bothered by the use of fear in the HIV messages and they believed that such messages were not likely to motivate people to change their behaviour.

In an opinion paper based on other surveys, interviews with international practitioners and personal experience E. Green and Witte (2006) note that there are differences in the perception of the effectiveness of fear appeal in HIV and AIDS messages. They state that American experts reject the use of fear in HIV and AIDS messages to appeal to people to change their behaviour as unethical and misguided. On the other hand, the paper notes that in Africa HIV and AIDS experts have embraced the use of fear appeal in HIV and AIDS messages. E. Green and Witte make reference to the case of Uganda where HIV and AIDS experts argued that HIV and AIDS campaign in that country was successful because they instilled fear in people. However, commenting on the effectiveness of fear appeal in HIV messages, Albright (2007) claims that fear messages are less likely to influence young people as at their age youths are normally not concerned about their death.

Blumberg (2000) presents an information processing model which proposes that HIV and AIDS information is processed at four levels. These are: pre-attention, focal attention, comprehension, and elaboration and assessment. The model explains the processing of fear provoking HIV and AIDS messages by suggesting four exit points on the information processing journey. Blumberg proposes that a person processing fear provoking HIV and AIDS information can exit by avoiding attention and comprehension. In addition, after comprehending the information a person can avoid making inferences to their life situation. Lastly, people can protect themselves by rejecting the message or denying vulnerability. Blumberg's model suggests that claims of successes of fear provoking information campaigns such as by E. Green and Witte (2006) are by chance.

Using data from a large community anonymous survey Essien, Ross, Linares, and Osemene (2000) investigated HIV information sources preferences and perceptions of reliability. The data were based on qualitative interviews with African Americans, Hispanic Americans and White Americans in Houston, Texas. The results of the study revealed that information provided by government agencies and professionals was perceived as more reliable among all ethnic groups. Information from family, friends and schools was perceived to be less reliable.

Gellaitry et al. (2005) investigated patients' satisfaction with information they received about antiretroviral therapy (ART) from different sources. The study was a quantitative longitudinal study of patients attending HIV clinics in Brighton, UK. A sample of one hundred seventy-four patients completed a questionnaire and a Patient Assessment of Sources of Medicines Information Questionnaire (PASMIQ). The results were consistent with those from Essien et al.'s (2000) study, and indicated that 42% of the respondents were more than 80% satisfied with ART information they received. In addition, 22% were 100% satisfied with ART information. The study also reported that participants who declined ART were those that were not satisfied with the information they received. Further, the study indicated that participants who held stronger concerns about ART were less satisfied with the information given.

In a study conducted in USA by Sutton, Anthony, Vila, McLellan-Lemal, and Weidle (2010) the results suggested that people were indifferent towards HIV and AIDS information. Sutton et al. conducted three surveys (a survey of three hundred twenty-six health departments, a survey of two hundred fifty HIV testing centres, and a survey of one hundred fifty-two HIV treatment centres) in ten states of USA. The study reported that HIV and AIDS information campaigns were hampered by lack of education of the target population, and underestimation of personal risk factors regarding HIV infection. Sutton et al. observed that indifference towards HIV and AIDS information was the reason behind the inaccurate risk perception. However, Blumberg (2000) suggests that sometimes people just avoid messages that provoke fear. Blumberg argues that people use cues from previous experiences with fear provoking information to identify and avoid processing similar information in future.

2.6.3   Access to HIV and AIDS information

The process of accessing information has physical, intellectual, and social aspects (Burnett et al., 2008).Further, it is an individual and interpersonal process, and most of the times affected by socioeconomic status, knowledge, skills, and perceptions of the information seeker (Burnett et al., 2008; Huber and Cruz, 2000). Sligo and Jameson (2000) contend that people favour information that is validated by their communities and from sources that have been accepted by their communities. Information therefore needs to be compatible with one's cultural framework and community's social norms in order to legitimise and reduce the taboos that are associated with certain types of information.

Studies conducted in the United States of America (Zukoski, Thorburn, and Stroud, 2011) and United Kingdom (Mukherjee and Bawden, 2012) indicated doctors, internet, health service (Mukherjee and Bawden, 2012; Zukoski et al., 2011) books and libraries (Mukherjee and

Bawden, 2012) as primary sources of information. In contrast, studies done in Africa indicate that people get HIV information from radio, television, non-governmental organizations, community based organizations (Albright and Kawooya, 2005a; Albright et al., 2007; Manda, 2007) health personnel, local leaders, peers and family members (Manda, 2007) and, films, posters and plays. Nwagwu (2008) reported that friends or relatives emerged as the most effective source of AIDS information for women and for girls television was most effective source.

Mosha and Manda (2012) reported that although youths were aware of reliable sources of HIV and AIDS information, they chose not to use those sources because of religious and cultural barriers. The study used questionnaires to collect data from a purposive sample of one hundred fifty-one undergraduate students in two university colleges in Tanzania. The results indicated that some sources were not used or trusted because of their conflict with the Christian faith teachings. In addition, students reported that although they recognised that their parents were trusted sources of information, they could not freely discuss HIV and AIDS issues owing to its taboo nature in most African cultures.

Another quantitative study using a random sample of four hundred thirty university students found that the least preferred information sources were the most frequently used. In the study Sammarco, Ripabelli, Ferrucci, and Grasso (2012) used questionnaires to collect data on the sources the participants got HIV and AIDS information from, and how useful the students found those sources for providing HIV and AIDS information. The results of the study indicated that 77.7% of the students accessed HIV and AIDS information from television and radio which were preferred by only 29.4% of the respondents. In addition, the second most frequently used source was the printed press with 61.3% of the respondents using it and only 35.3% of the respondents preferring the printed press.

In another study investigating ways how information can assist people living with HIV to live a better life, Hogan and Palmer (2005) reported some barriers to use of HIV information. The study used a postal survey and six hundred sixty-two usable questionnaires were returned. The questionnaire solicited data on information needs of, and information sources used by people living with HIV. It also asked questions about the barriers they faced in the process of seeking HIV and AIDS information. The study found that 70% of the respondents indicated doctors in the top three preferred sources of HIV and AIDS information. In addition, 35% and 33% preferred HIV positive counsellors and magazines respectively. However, respondents reported that the three most important barriers to accessing HIV and AIDS information are that the information was hard to understand, it was not trustworthy, and too much.

A study on how HIV positive people collaborate to meet their treatment information needs by O'Grady (2008) identified stigma as a major barrier to accessing HIV information. The study used focus group discussions to collect data from a purposive sample of people who had a need for treatment information related to HIV and AIDS and had access to internet. The objective was to determine how people living with HIV were collaborating to meet their HIV treatment information needs. The study results indicated that people living with HIV were concerned about the credibility of sources of information. As such they tended to seek information from sources that were familiar and easy to access. In addition, the study found that stigma was major factor that was considered when choosing sources for HIV and AIDS information.

Modern technologies including mobile phones and internet have the potential to improve access to HIV and AIDS information for people living with HIV. Kalichman et al. (2002) investigated patterns of internet use for health information among people living with HIV. The study recruited a purposive sample of ninety-six men and fifty-one women living with HIV. Participants were assessed for competency working with internet using a basic computer and internet test. They were also screened for reading ability using the reading comprehension section of the test of functional health literacy for adults. The rest of the data collection was done using an inventory regarding computer and internet use which was completed by the participants. The results indicated that internet and computer use were not associated with participants' demographic factors and HIV related symptoms or hospitalisation. However, internet and computer use were closely associated with years of education and income. People with twelve years or less of education reported very low computer and internet usage.

Mbananga and Becker (2002) investigated the capability of modern technologies to transmit HIV and AIDS messages in South Africa. A stratified sample was decided by first selecting a village from a list of villages from Umtata District by using random numbers, and secondly choosing every fifth household on the village's row. The study surveyed urban and rural communities to assess readability and comprehension of reproductive health messages. The results suggested that people from rural areas listened to the radio more than people from urban areas who watched television more. In addition, the study found that in both urban and rural areas women were able to understand reading HIV and AIDS materials more than men.

The barriers or constraints to information access and use identified by studies reviewed in this section are what are called intervening variables in Wilson's Model of Information Behaviour. The studies identified psychological intervening variables such as stigma (O'Grady, 2008), demographic intervening variables such as religion and culture (Mosha and Manda, 2012), and

source characteristics such us difficulty to understand the information (Hogan and Palmer, 2005), and credibility of the sources (Hogan and Palmer, 2005; O'Grady, 2008). On the other hand, Chatman's Theory of Life in the Round is also reflected in the findings of these studies. The participants in Mosha and Manda's (2012) study lived in a small world where social norms and world view were defined by religion and culture. Therefore, any information that contradicted religion and culture was rejected. Similarly, Hogan and Palmer (2005) and O'Grady (2008) reported that participants questioned the credibility of some information sources. In Hogan and Palmer's (2005) study doctors and people in the respondents' personal lives were indicated as highly trusted sources. One could speculate that the sources that were not trusted were ones that were considered alien to the respondents "small world".

2.6.3.1 Language and access to HIV and AIDS information

Access to HIV and AIDS information can also be viewed in the context of language. Kamwendo (2008) observes that although some countries in sub-Saharan Africa are classed as Anglophone, most people living in these countries are not competent in the English language. Further, Namyalo (2010) notes that the lack of standardised HIV and AIDS terminologies in Uganda results in translation of information materials from English to local languages being imprecise and in some cases offensive. Lubinga and Jansen (2011) investigated the effect of communicating HIV and AIDS messages in the local language rather than English. In their study, Lubinga and Jansen used interviews to investigate the appreciation and comprehension of HIV and AIDS messages translated from English to the local languages in South Africa. The interviews were conducted with a random sample of bi-lingual (English, and a South African mother language) students. The study found that translation of the messages into the local languages did not have any effect on comprehension.

A similar study with different results was conducted by Magonya (2012) in Kenya. The objective of the study was to investigate whether HIV and AIDS posters in Kenya were viewed as explicit and easy to comprehend. Magonya used a cross-sectional survey of a random sample of twenty-eight people. The study also evaluated sources of HIV and AIDS messages with the aim of soliciting the participants' views about the sources. Magonya found that participants viewed some words used on HIV and AIDS posters as culturally inappropriate and obscene. She further observes that this finding was due to a deficit of culturally appropriate terminologies that can be used for some HIV and AIDS notions.

In their study, Cain, Schensul, and Mlobeli (2011) observe that HIV and AIDS interventions use explicit and detailed description of human sexuality in order to communicate the risks of HIV. In

addition, Cain et al. concede that in most African cultures "the language that is permissible varies dramatically in public and private settings, among single and mixed gender groups, among older and younger people and for the objectives of titillation versus education" (pp. 476). Cain et al. (2011) used in-depth interviews to investigate terminology used for male and female genitalia, and sexual intercourse that are culturally appropriate for HIV and AIDS communication among Xhosa people of South Africa. The findings of the study were that appropriate terms were those that reflected the gender identity and social status of the speaker. In addition, appropriate terms reflected the social context in which the communication is made. Terminology that is appropriate is that which respects gender roles.

Mupenda et al. (2014) investigated terminologies used in public discourse regarding HIV and AIDS in the Democratic Republic of the Congo. Participants for the study were twenty-nine randomly selected young people living with HIV receiving care in Kinshasa. The study found that terms used to describe HIV and AIDS were mostly derogatory, describing people living with HIV as walking corpses, deserving to die, and danger to others. Mupenda et al. contends that most of terms used to describe HIV and AIDS show that people are trying to understand it but it remains unfamiliar. On the other hand, the study found that some labels are used to describe people living with HIV in order to make their HIV status anonymous.

2.6.4   HIV and AIDS information sources

Studies have shown that the major sources of HIV and AIDS information for PLWHA are AIDS newsletters, doctors, magazines, personal physicians, pamphlets, brochures, friends (Hogan and Palmer, 2005; Huber and Cruz, 2000; Veinot, 2009a), HIV positive counselors (Hogan and Palmer, 2005), newspapers, books (Huber and Cruz, 2000), television (Huber and Cruz, 2000; Manda, 2007), radio, family members, non-governmental organisations (NGOs), Community-based organisations (CBOs), and schools (Manda, 2007).

HIV and AIDS information sources reported by Hogan and Palmer (2005), Huber and Cruz (2000), Veinot (2009a) and Manda (2007) could be similar to those used by PLWHA in Malawi. However, there are other factors that may affect or limit acceptability of information sources and the information. "Within any given small world, there are a variety of ways in which individuals may behave in relation to the information available to them. For example, they might perceive the act of actively seeking for information to be costly or difficult, and thus avoid it. Or they may view information available to them as important, but may reach the conclusion that they can get along without it. Or, further, they may believe that the information comes from unacceptable social type, and thus conclude that the information, even if it is accurate, is itself unacceptable" (Burnett et al.,

2001, p. 538). Besides, Chatman (2000) as quoted by Burnett et al. (2008) contends that in a small world, people tend to judge the authenticity of information based on the source. If information is coming from someone perceived as an outsider or from a source whose characteristics conflict with the norms or worldview of their small world it is ignored. Small world has routine and expected ways of doing business based on social norms and worldview (Burnett et al., 2001).

Music has been found to be effective in disseminating HIV and AIDS messages (Banda and Mambwe, 2013; Bastien, 2009). Bastien (2009) investigated the role of music in disseminating information about HIV and AIDS in Tanzania. The study used data collected as part of a bigger study on how HIV and AIDS are communicated to out of school youths. The bigger study conducted structured face-to-face interviews with one thousand and seven young people between the ages of 13 and 18 (Bastien, 2008). This data was then supplemented by in-depth interviews with sixty-five young people, and an analysis of seven songs identified during the interviews. On the other hand Banda and Mambwe (2013) conducted a discourse analysis of fifty song lyrics and videos that had HIV and AIDS messages produced between 2009 and 2011. While Bastien reports that music and songs are effective in disseminating culturally relevant HIV and AIDS messages, Banda and Mambwe identified contradictions in the messages. Banda and Mambwe contend that the contradictions are counterproductive to the fight against HIV. Most lyrics in HIV and AIDS songs were found to portray women negatively (Banda and Mambwe, 2013; Lwanda, 2011).

2.6.4.1   Libraries, Internet, and access to HIV and AIDS information
Many studies have identified libraries and internet as sources of HIV and AIDS information (Kalichman et al., 2002; Mosha and Manda, 2012). However, a study conducted in Nigeria by Edewor (2010) found that people living with HIV were not using libraries as a source of HIV and AIDS information. The study adopted a survey research design and used a random sample of one hundred twenty people living with HIV to investigate the challenges people living with HIV face when accessing HIV and AIDS information. Edewor observed that libraries were not involved enough in making HIV and AIDS information available to people living with HIV.

A multi-country study carried out in Ethiopia, Ghana, Kenya, Tanzania, Uganda and Zimbabwe by Elbert, Fuegi, and Lipeikaite (2011) investigated different stakeholders' perceptions of public libraries. The study used a survey approach and found that typically public libraries are used by young people who are in school or just completed school, aged between 16 and 30 and from a middle class back ground. The study findings suggests, that other than for education related

information needs, public libraries are not used as sources of information for everyday problems. These findings were corroborated by (Kaunda, 2013) conducted in Malawi. Kaunda used focus-group discussions and a survey to assess user needs and measure satisfaction with public library services. The study found that over 50% of public library users in Malawi are students. Public libraries were also found to be used by unemployed adults looking for job adverts in newspapers.

Musoke's (2014) project report probably suggests some clues regarding reasons for non-use of libraries in Africa. One strand of the project was aimed at empowering communities in solving health problems. This strand involved the library facilitating information sessions run by health workers for local communities. The project was positively evaluated by community members. Insights from the project suggest that communities will use library services that are relevant and within reach.

Another important source of HIV and AIDS information is the Internet. ICT services in Africa have improved in the recent past. Mobile network coverage in Africa has increased from 16% in the late 1990s to 90% of the population in 2011 (The World Bank and African Development Bank, 2012). The World Bank and African Development Bank further state that trends in ICT usage in Africa suggest that ICT can assist in addressing the health challenges in rural Africa. However, Edejer (2000) contends that even if people in developing countries have access to health information on the internet, they would still be faced with challenges of accuracy and relevance of the information.

Kalichman et al's (2002) findings on internet use in USA reviewed earlier in this section contrast those from studies conducted in Malawi. In Malawi, a national survey of adolescents was conducted by Munthali et al. (2006a) to collect data on knowledge, attitudes and practices that protect or put adolescents at risk of HIV infection. The study found that less than 1% of the adolescents surveyed had ever used internet. Similarly, Gombachika, Chirwa, Malata, and Maluwa (2013) investigated sources of information for reproductive health decisions for couples living with HIV in Malawi. The study used in-depth interviews to explore the sources of HIV and AIDS information the couples used for decision making. Among the sources of HIV and AIDS information reported by Gombachika et al. internet was not one of them. These two studies taken together suggest that internet services are scarce in Malawi and that most Malawians are not skilled enough to benefit from internet.

Mobile phones have the potential to contribute to health promotion in Africa (Clouse et al., 2015; Puri et al., 2010). Puri et al. (2010) used mixed methods to investigate the effects mobile network

strengthening on the villages in Ghana, Kenya, Nigeria and Tanzania. A survey was used to collect baseline data from one thousand and twenty-one representative households, and two hundred thirty-five semi-structured interviews were conducted to collect qualitative data. The study found that ICTs have the potential to accelerate the attainment of Millennium Development Goals (MDG) by improving communication and access to information. However, millennium villages are projects where mobile phones are used as part of the interventions to stimulate socio-economic development; therefore they do not represent a typical village in Africa. Clouse et al. (2015) investigated mobile phone usage among HIV positive pregnant women attending antenatal clinic in South Africa. Data for the study were collected using semi-structured interviews from a purposive sample of fifty women. In general the results were consistent with those from Puri et al.'s study. However, Clouse et al. found that despite all mobile phones owned by the women having internet capabilities, only a few women used their phones to access internet. In addition, Clouse et al. identified some confidentiality issues with the use of mobiles phones for sending health messages as many women shared their phones with others.

Social media is identified as a source of HIV and AIDS information with growing importance (Guo and Goh, 2014; Jaganath, Gill, Cohen, and Young, 2012; Mo and Coulson, 2008). Jaganath et al. (2012) carried out a longitudinal experiment to assess the effectiveness and acceptability of social media for disseminating HIV and AIDS information. The study, called Harnessing Online Peer Education (HOPE), recruited peer leaders who represented the target population. The criteria for recruiting peer leaders was that they should be male who have sex with other men, over 18 years old and have experience using Facebook. The participants were randomly assigned to the experimental and control groups. The control group was trained to equip them with knowledge and skills in HIV and AIDS, social context, communication, and ethics. Reporting on the same study Young, Shoptaw, Harrell, Jaganath, and Cohen (2013) state that peer leaders in the experimental group developed confidence in discussing HIV and AIDS related topics. The study demonstrated that peer health educators can effectively be recruited and trained to use social media for behaviour change interventions.

Studies show that social media is used for emotional support, sharing medical information (Guo and Goh, 2014; Mo and Coulson, 2008), exchanging intimacy relationship messages (Guo and Goh, 2014), and networking (Mo and Coulson, 2008). Guo and Goh, and Mo and Coulson used content analysis of messages posted by members of social media group members. Guo and Goh observed that as time passed members of the line groups started exchanging personal contact details for one-on-one chatting. Furthermore, people from same locations started forming separate online groups which were culturally homogeneous. In general, groups on social media

assisted people living with HIV to redefine their negative situations through sharing of personal experiences (Mo and Coulson, 2008).

2.6.5   HIV and AIDS information, and couples

Studies reviewed in this section are on the clinical aspects of HIV and AIDS. Though not from information science discipline, and specifically not from information behaviour research, they highlight intervening variables as described by Wilson (1999) and Wilson (1997).

Married couple relationships are defined differently in different cultural contexts. Although the African family structures are diverse, they share common characteristics in their "emphasis on extended family, multiple marriage forms, high levels of child bearing, segregated gender roles, and strong intergenerational ties" (Oheneba-Sakyi and Takyi, 2007, p. 18). Despite resilience in preserving these characteristics, Oheneba-Sakyi and Takyi (2007) observes that African families are being threatened by the HIV and AIDS pandemic.

Unprotected sex is identified as one of the major drivers of the HIV pandemic (World Health Organization et al., 2011). In addition the Joint United Nations Programme on HIV/AIDS (2012b) states that providing HIV and AIDS preventive services jointly to couples significantly reduces the risk of HIV transmission between partners.

Gombachika et al. (2012) used informant interviews to explore barriers to accessing sexual and reproductive services among couples living with HIV in Malawi. A purposive sample of twenty couples living with HIV was recruited from antiretroviral therapy clinics. The study identified barriers that were categorised as personal, interpersonal, community, organizational, and societal. Among the barriers that are relevant to this study was lack of literacy skills to read written media communicating HIV and AIDS, and reproductive health information. The study also found that couples living with HIV were receiving conflicting HIV and AIDS information from different sources. The couples reported that while HIV and AIDS radio programmes were advocating that it is possible for couples living with HIV to have HIV negative children, counsellors in the health facilities were against such messages.

A paper by Anglewicz, Bignami-Van Assche, Clark, and Mkandawire (2010) which was based on Malawi Diffusion and Ideational Change Project (MDICP) indicates that both men and women believed that the husband's infidelity put both partners at HIV infection risk. MDICP was a population based survey with a random sample one thousand five hundred women and one thousand men in monogamous marriages. The results also showed that women did not see their infidelity was an HIV risk factor for themselves and their husbands.

The issue of vulnerability and risk regarding HIV were also explored by Ghosh and Kalipeni (2005) in Malawi. Ghosh and Kalipeni administered a structured questionnaire to a random sample of sixty women, and conducted two focus group interviews of ten women each. The study found that 93% of the women had heard about HIV and AIDS at the clinic, on the radio or from health workers visiting their communities. In addition, all women were aware that they could get HIV after having un-protected sex with someone who looked healthy. However, 86% of the women said they would not use condoms with their husbands. Ghosh and Kalipeni (2005) observe that because of their low economic status, and inferior position women in Malawi engage in sexual activities that put them at risk of getting infected with HIV.

The factors affecting access and use of HIV and AIDS information identified in studies reviewed in this section resonate with intervening variables in Wilson's (1996) Model of Information Behaviour. These include literacy skills of the recipients, conflicting messages from different sources, and risk perception. Furthermore, studies reviewed in this section suggest that sex within marriage was viewed as safe.

2.6.6   HIV and AIDS information in Malawi

To the best of my knowledge, not much has been published on the information behaviour of people living with HIV and AIDS in Malawi. The implementation plan for information, education and communication interventions for HIV and AIDS produced by Malawi Government (2003) indicated that one of the barrier to behaviour change is lack of community involvement in HIV and AIDS issues. Further, the plan states that there was inadequate HIV and AIDS related information, education and communication materials provided to people. Seven years later, in 2010 National Statistical Office (NSO) and ICF Macro (2011) reported that 99% of people in Malawi were aware of HIV and AIDS. However, Malawi Government (2012a) states that this had not translated into behaviour change. Albright (2007) asserts that dissemination of HIV and AIDS information in Sub-Saharan Africa fail because they use strategies, such as mass media, that fail to guarantee tailoring of HIV and AIDS messages to specific cultures.

In an opinion paper Bandawe (2004) argues that HIV information services in Malawi are not effective because they are based on the assumption that after people receive the information, they will automatically change their behaviour. Bandawe contends that these messages are targeted at the cognitive structures of the recipients of the messages ignoring the peer influences they receive from those around them. This was confirmed in a study conducted by Houston and Hovorka (2007) in Dedza District in Malawi where HIV information flow in a district was investigated. They used relational analysis to explore relationships between institutional and

personal actors in HIV and AIDS information provision, and interaction and flow of HIV and AIDS information. Egocentric analysis was also used to map HIV and AIDS social networks individuals were involved in and how people received information. The study found that due to strong family ties, solidarity, and oral tradition of the African culture, people were more influenced by HIV information obtained from personal sources such as family, friends, religious leaders, and traditional healers.

The study also investigated how HIV information was received and negotiated by individuals at the local level. The study found that there were conflicting messages going out to people at the local level. Government agencies, local hospitals and non-governmental organisations promoted Western solutions to the HIV pandemic. These included condom use, and voluntary testing and counselling. On the other hand, teachers, religious leaders, traditional leaders, and traditional healers promoted HIV and AIDS messages that embraced cultural values and beliefs. Particularly, these messages were found to be negative about condom use, linking it to promiscuity.

Edriss and Kaunda (2000) reported that some HIV and AIDS information provided by Government agencies in Malawi had contradictory messages. Data were collected from a sample of one thousand two hundred twenty students using a structured questionnaire to investigate their perceptions of HIV and AIDS messages. The study results suggested that people believed that only people who had multiple sexual partners were at risk of contracting HIV. According to Edriss and Kaunda, this was a result of the emphasis in the messages that sex workers and people with multiple sex partners are at risk of HIV. The study also found that parents thought more open HIV and AIDS information were obscene and therefore not suitable for their children. This is consistent with the findings of Houston and Hovorka's (2007) study where teachers, religious leaders and traditional healers promoted HIV and AIDS messages that emphasised cultural and moral values. In addition, the findings of the two studies are in agreement with Chatman's Theory of Information Poverty and Chatman's Theory of Life in the Round.

In 2009 Knowledge for Health (K4Health) conducted a study in Malawi to assess the reproductive health, and HIV and AIDS information needs of managers of reproductive health programmes (LeMay and Bocock, 2012). The study found that health workers, especially at the community level, had limited access to relevant and up-to-date reproductive health, and HIV and AIDS information. The health workers indicated that sometimes the reproductive health, and HIV and AIDS information they access to be too dense for them. They reported that they needed information that is segmented, synthesised and summarised.

2.6.7 Summary for section 2.6

People living with HIV need information to manage the HIV infection and other opportunistic infections (Edewor, 2010; Huber and Cruz, 2000; Selman et al., 2009). They also need information on social, economic and religious aspects of their lives (Huber and Cruz, 2000). Many studies have documented the sources that are used to access information by people living with HIV. These include hospital, family and friends, peers (Gombachika et al., 2013), music (Bastien, 2009), and internet (Kalichman et al., 2002). Although, libraries and internet are identified as sources of HIV and AIDS information, other studies suggest that libraries in Africa are predominantly used for education purposes and not for information for everyday problems(Elbert et al., 2011; Kaunda, 2013). The other source that identified as having potential to be used to disseminate HIV and AIDS information in Africa is the internet (Kalichman et al., 2002). However, many people in Malawi are not skilled enough to benefit from the internet and services are not well developed (Munthali et al., 2006a).

There being no cure for HIV, information has been the most vital tool for managing the HIV pandemic. However, only some HIV and AIDS information interventions are successful. The success of Uganda's approach is well documented in studies reviewed in this section. The important success factors of HIV and AIDS information programmes identified for Uganda are cultural sensitivity and multi-sectoral collaboration. Sexual behaviours and attitudes concerning what constitutes sexual risk behaviour are socially constructed (Uwah and Wright, 2012). Therefore, if HIV and AIDS information campaigns are to be successful, they need to be designed with awareness of cultural contexts of the target populations (Manda, 2007; Uwah and Wright, 2012). In addition, it is important for various players in delivering HIV and AIDS information should work in unison (Albright and Kawooya, 2005a; Muchini et al., 2011).

Studies reviewed in this section have shown that knowledge about HIV and AIDS is a determinant of health seeking. People that are knowledgeable about HIV and AIDS are more likely to accept HIV testing. However, most people's knowledge about HIV and AIDS is limited (Audet et al., 2012; Ayenew et al., 2010). One of the factors identified as affecting acquisition of knowledge on HIV and AIDS is the use of language that arouses fear (Bastien, 2011; E. Green and Witte, 2006).

2.7   Chapter conclusion: Implications of the literature on the study

This chapter will conclude with a discussion of the implications of the literature reviewed in this section on the study. The literature reviewed demonstrates the importance of serodiscordant couples in the fight against the HIV and AIDS pandemic. World Health Organisation and Joint

United Nations Programme on HIV/AIDS (2009) and Malawi Government (2012a) identified serodiscordant couples as a priority group in the fight against the HIV and AIDS pandemic.

Burnett et al. (2001), quoting Cooley (1956), state that people who are marginalized have a limited view of the larger world. Further, as stated by Burnett et al. (2001), they may believe that HIV and AIDS information available to them comes from unacceptable sources. Information behaviour theories reviewed suggest that when people view an information source as unacceptable, they conclude that the information itself is unacceptable.

The literature reviewed has shown that among serodiscordant couples decisions are not only influenced by HIV and AIDS information obtained from formal sources. Since these couples are members of their societies, they are forced to live up to the expectations of those communities. Studies have shown that social expectations demand that these couples bear children despite their HIV status (S. Allen et al., 2003; Beyeza-Kashesya et al., 2010; Hailemariam et al., 2012). On the other hand, couples that were HIV positive were forced to engage in secretive behaviour in order to survive stigma and discrimination (Veinot, 2009b). This aspect of the lives of HIV positive couples points to ethical implications of studies like mine. If HIV positive couples are not assured of privacy and confidentiality they can choose not to interact with others.

The literature reviewed also shows that health information in general, and HIV and AIDS information in particular is affected by religious, cultural and moral factors. When HIV and AIDS information contradict religious, cultural and moral values, the information becomes unacceptable (Mosha and Manda, 2012). Other studies reviewed in this chapter indicated that people have multiple sources of HIV and AIDS information, some of which conflict with each other. These studies allude to the complex and contextual nature of information in general and HIV and AIDS information in particular.

The literature suggests that information access has a physical aspect, social aspect, and intellectual aspect (Burnett et al., 2008). In addition, the literature shows that information is used and interpreted with a context. This is also in line with Wilson's Model of Information Behaviour. This, coupled with religious, cultural and moral factors affecting HIV information discussed earlier imply that context is an important aspect in information behaviour research. Case (2012) contends that information needs arise from a person's history, predispositions, purpose, and motivations.

The theories of information behaviour reviewed indicate that people can actively or passively seek information (Wilson, 1999). With respect to the serodiscordant couples, this implies that they experience HIV and AIDS information even when they are not actively seeking.

From the literature reviewed it would appear that some studies that used quantitative methods only identified factors that affect access and use of HIV and AIDS information. The studies would have benefited from qualitative approaches to delve into the reasons behind the factors identified. In addition, the literature suggests that phenomenology is not widely used in library and information research. Most qualitative studies reviewed used ethnography and phenomenography.

The literature reviewed in this chapter indicates that information behaviour research related to HIV and AIDS has largely focused on the HIV and AIDS in general. Very few studies appear to have been published on information behaviour of specific groups such as serodiscordant couples. In addition, the literature suggests that information experience in an emerging domain of research within information behavior.

Chapter 3

Research process

3.1 Introduction

This chapter will contrast different approaches to social enquiry. The different philosophical assumptions researchers make about social reality are discussed first. A discussion of ontological and epistemological assumptions is considered appropriate in order to position the study in a worldview. Further, three qualitative research approaches are discussed based on the extent to which they assist answering the research questions. In conclusion, the chapter discusses the ontological, epistemological and paradigmatic stance of the study. A discussion of these in relation to my study will be done in chapter 4.

3.1.1 Research questions

How do serodiscordant couples experience HIV and AIDS information in Malawi?

Sub-questions

1. What HIV and AIDS information do serodiscordant couples in Malawi need?

2. From what sources do serodiscordant couples get HIV and AIDS information?

3. How do serodiscordant couples make sense of HIV and AIDS information?

4. How has the experience of discordancy affected the couples' information world?

3.1.2 What is experience?

The Oxford English Dictionary defines experience as "the fact of being consciously the subject of a state or condition, or of being consciously affected by an event" (Oxford University Press, 2000). According to Schwandt (2001, p. 86) experience uses a particular process, has a history and dynamic character. Schwandt defines experience as "something one undergoes so that subjectivity is drawn into an 'event' of meaning".

For the purposes of this study experience is defined as a person being consciously affected by phenomena through which subjectivity is drawn into meaning (Oxford University Press, 2000; Schwandt, 2001).

3.2   Research philosophies

Qualitative researchers make philosophical assumptions that guide the inquiry of the social world. These assumptions combine ontology, epistemology, axiology and methodology (Denzin and Lincoln, 2011a). It is therefore appropriate at this point to discuss the philosophical assumptions that guided the choice of research methods for this study. As stated by Wilson (2003), when a researcher picks a method it should be based on a philosophical framework that justifies why that particular method is chosen. Wilson further advises that method should be compatible with the view of reality held by the researcher.

My ontological position is that reality is constructed by people's interactions and through language. Further, I believe that there is no single reality. Based on these beliefs I subscribe to the relativist ontological position. Following from the ontological stance, I believe that in order to gain knowledge of the social world researchers need to interact with people occupying that world. In addition, I believe that research is value laden. Specifically, I subscribe to relativist ontological and subjectivist epistemological stances. I will now discuss the ontological, epistemological and axiological assumptions that guide social enquiry including my stance.

3.2.1   Ontological assumptions

Ontology is concerned with researchers' assumptions about the nature of reality and commitment held to particular views (Saunders, Lewis, and Thornhill, 2009). Bryman (2012) states that the central point for ontological considerations in social enquiry is the question of whether social phenomena should be considered as objective entities, having reality external to social actors, or should be considered as being constructed through the social interactions of social actors. In this section three ontological perspectives will be discussed: realism, critical realism, and relativism.

Realism is the ontological position that maintains that there is reality that exists independent of the knower's knowledge of its existence (Schwandt, 2001). Varieties of realism that are commonly identified by commentators are empirical realism, critical realism and historical realism (Blaikie, 2010; Bryman, 2012; Lincoln, Lynham, and Guba, 2011; Schwandt, 2001).

Empirical realism, also labelled "naïve" realism, asserts that all that exists is that which we can observe (Blaikie, 2010). Reality exists independent of, or external to, the knower, it is observable, and the challenge is for social scientists to make the observations and describe it (Blaikie, 2010; Lincoln et al., 2011).

Critical realism is associated with the philosophical writings of Roy Bhaskar. The ontological stance of critical realism is that there is objective reality independent of, and external to, the knower but this reality is subject to uncertainty and probability (Pickard, 2007).

Historical realism concerns a historical reality or events that occurred in the past even though these cannot be observed now (McCullagh, 1980). It asserts that reality is virtual, shaped by a disorderly collection of social, political, cultural, economic, ethnic, and gender factors and then concretized into structures that are taken as real (Guba and Lincoln, 1994; Lincoln et al., 2011).

Relativism is the ontological stance that maintains that reality is determined by the language and fundamental beliefs that people hold (Schwandt, 2001). In addition, reality is viewed as intersubjectively constructed through social interactions and experience (Lincoln, Lynham & Guba, 2011). Therefore, it is not possible to have objective reality since different cultures and societies have different language and belief systems (Robson, 2002). Guba and Lincoln (1994) state that relativists apprehend social reality as multiple, intangible mental constructions that are social, and specific to individuals and local contexts. They state that at the same time reality is constructed intersubjectively through the meanings and understandings people draw from their social interactions and experiences. "Intersubjectivity" refers to the shared construction of reality between or among two or more people (Schwandt, 2001). Relativism is often linked to the philosophy of Thomas Kuhn.

3.2.2 Epistemology

Epistemology concerns the claims we make about knowledge and how those claims can be justified (Schwandt, 2001). Bryman (2012) explains that epistemological issues address the question of what should be accepted as legitimate knowledge in a discipline. Although there are several schools of thought, the dominant ones are objectivism and subjectivism.

Objectivism is the epistemological position that posits that a researcher should detach him/herself from reality and explain it using universal laws (Abma and Widdershoven, 2011). In this case, reality is pre-given, has intrinsic meaning and the role of the knower is to discover that meaning (Blaikie, 2010). Objectivists argue that, for example, if we are able to observe a plant grow and report on it, then we can also observe human beings interact with their environment and report on it (Pickard, 2007).

Subjectivism is the philosophical belief that people construct their own understanding of social reality based on their interactions with their environment (Lincoln et al., 2011). Further, Lincoln et al state that for a researcher who holds subjectivist epistemology the findings come from the

interaction with research participants. The researchers' lived experience plays a part in the knowledge they generate with research participants.

3.2.3   Axiological assumptions

Axiology concerns the theory of values that inform how researchers see the social world and the value judgments they make throughout the research (Walter, 2010). On the role of values in social research, researchers are spread on a continuum ranging from those believing that research should be carried out in a value free manner to those who believe research is value laden (Teddlie and Tashakkori, 2009). The arguments for the inevitable value laden nature of research are based on the understanding that social phenomena that are studied occur in real world where moral, political and cultural values are an integral part of the social landscape (Walter, 2010). Researchers who accept that research is value laden actively and reflexively acknowledge and report their own values and biases. In addition, they acknowledge that the data that are collected from the field are also value laden (Creswell, 2007).

Mertens (2010) contends that whatever paradigm a researcher uses, ethical issues should be addressed throughout the study and should not be an afterthought. As stated by Christians (2011), the convention for social research is to use codes of ethics which have four common guidelines: informed consent, avoidance of deception, privacy and confidentiality, and accuracy.

Ethical conduct of research demands that participants agree to participate voluntarily without physical or psychological coercion. In addition, this agreement to participate should be based on full and open information about the study (Christians, 2011). Wiles (2013) contends that researchers should ensure that they have consent from participants at all stages of the research process. This gives participants the right to withdraw their consent any time during the study.

Related to informed consent is the requirement that researchers need to explain the purpose of the study without being deceptive about the nature of the research (Creswell, 2007). However, Creswell (2007) and Christians (2011) contend there may be studies where if participants are told the nature of the study they would not participate. They argue that if the information that would be obtained from these studies is valuable to society deception can be permitted.

The conduct of social inquiry can sometimes intrude on people's privacy and seek information that is sensitive (Punch, 2006). In order to protect research participants, researchers are required to protect their identities and those of the research sites. This can be achieved by pseudonyms and codes in order to make the identities of people and places anonymous (Christians, 2011). Although maintaining the anonymity of research participants appears to be the default position,

there is need to realise that other participants might not want to remain anonymous. When one of the aims of qualitative research is to give voice to people that are marginalised, Giordano, O'Reilly, Taylor, and Dogra (2007) argue that enforcing confidentiality would also be reinforcing the inequalities of power between the researcher and the participant. Further, Giordano et al contend that if researchers trust participants to make informed decisions about their participation in a study, they should also trust them to make informed decisions on whether to waive anonymity or not.

Another ethical issue concerns data that are collected. Researchers are required to be honest and not use fraudulent and fabricated data in their studies. In addition, deliberately omitting some data with intentions to change the results is also unethical (Christians, 2011).

3.3   Research paradigms

Based on the ontological, epistemological and axiological assumptions that have been presented I will discuss four research paradigms that are commonly used in social research. Denzin and Lincoln (2011b) define paradigm as the basic set of beliefs that guide the conduct of social research. They state that a paradigm encompasses ontological, epistemological and axiological assumptions and methodology. Further, Blaikie (2010) posits that paradigms provide different ways of making connections between researchers' conceptions of the social world, people's experiences and the social world within which social life occur. The paradigms that will be discussed are positivism, postpositivism, critical theory, and constructivism.

3.3.1   Positivism

Positivism is associated with the French philosopher Auguste Comte (1798-1857) who argued that the goal of science is prediction (Schwandt, 2001). The positivists' view maintains that reality consists of orderly discrete events that can be measured and quantified using human senses (Blaikie, 2010). In addition, positivists contend that research should, as far as possible, be carried out in a purely objective and value free manner (Saunders et al., 2009). Thus, positivists make effort to control or eliminate the effect of values on the research process.

This paradigm is based on the belief that the knower should take an objectivist observer position in the field (Pickard, 2007). Positivists take a realist ontological position and believe that if research is done in a controlled manner with a representative sample, the results would be true to all members of the population under study (LeCompte and Schensul, 1999). In addition positivists take the objectivist epistemological stance, and believe that as much as possible researchers should remain detached from what they are studying so that they can find the objective truth

rather than findings contaminated by beliefs and values of the researcher (Payne and Payne, 2004).

3.3.2 Postpositivism

Postpositivism developed as a direct reaction to the shortcomings of positivism as a suitable method for studying human behaviour. For postpositivists, it is not possible to study social life using a positivist approach which is thought to be mechanistic (Pickard, 2007). In practice, postpositivist researchers use logical steps, and use rigorous methods of data collection and analysis (Creswell, 2003). Ontologically, postpositivists are critical realists, believing in an objective reality which is only knowable imperfectly (Robson, 2002). Epistemologically, postpositivists take an objectivist approach and argue that our knowledge of social reality is only an approximation (Lincoln et al., 2011). Postpositivists acknowledge that research is value laden and they enhance internal validity and external validity of the methods in order to reduce the influence of personal values on the conclusions (Teddlie and Tashakkori, 2009).

3.3.3 Critical theory

Critical theory is a paradigm whose main proponents are Max Horkheimer, Theodore Adorno, Herbert Marcuse, Erich Fromm and, Jurgen Habermas (Willmott, 2008). Critical theory is concerned with issues of social justice and marginalization with respect to issues such as feminism and race. Critical theorists endeavor to emancipate people from oppression. Thus, the quality of research from the critical standpoint is based on the extent to which it liberates the oppressed. Therefore, research in the critical theory paradigm tend to focus on how race, gender, religion, and ethnicity interact to cause inequalities (LeCompte and Schensul, 1999).

Researchers subscribing to this paradigm believe that reality is historical, shaped by gender, political, cultural, religious, and social values, and they adopt historical realist ontology (Lincoln et al., 2011). Critical theorists subscribe to the subjectivist epistemology; believing that knowledge is as a result of intersubjective social constructions. In addition, they reject claims that research is value free. Unlike the positivist paradigm where the aim of identifying values is to eliminate their effects, critical theorist believe that values are part and parcel of the phenomena under study (LeCompte and Schensul, 1999).

3.3.4 Constructivism

Constructivists maintain that social reality is a product of processes through which human beings make sense of their everyday actions and situations (Blaikie, 2011). Further, constructivists maintain that to understand human action researchers must understand the meaning inherent in those actions. The meaning of the actions is constructed from the context and through language

(Schwandt, 2000). Therefore research that uses the constructivist paradigm studies phenomena by investigating how people use language and symbols to construct their social reality (Klenke, 2008) Constructivists take a relativist ontological position and a subjectivist epistemological position (Lincoln et al., 2011). Further, constructivists argue that research is value laden (Teddlie and Tashakkori, 2009) and that it is impossible to ignore the moral, cultural and political values involved (Walter, 2010).

3.3.5   Summary

According to Creswell (2007) it is possible for a researcher to blend elements of two paradigms in one study. Lincoln et al. (2011) state that the boundaries between the paradigms are fluid and evolving. This means that the paradigms are dynamic much as social inquiry is also dynamic. Answering the question whether paradigms are commensurable, Lincoln et al. (2011) proceeds with a cautious *yes*. Lincoln et al argue that for example positivist and postpositivist paradigms can be commensurate, so can critical theory and constructivist paradigms. In addition, positivist and constructivist paradigms and their philosophical assumptions are not commensurable.

3.3.6   Ethics and HIV and AIDS research

Studies reviewed in Chapter 2 indicated that HIV and AIDS information is laden with religious, cultural and moral issues. Therefore as stated by Denscombe (2003), researchers should not take a privileged position in pursuit of their interests at the expense of people they are researching on. AIDS in African is considered a disease of the poor, of women who sell sex for food, of people who can't afford medical treatment (Nolen, 2008). Although this is not true, people living with HIV are stigmatised and taken advantage of. Rodrigues et al. (2013) investigated the understanding of research, and how decisions to participate in research were made among people living with HIV in India. The study found that people who have less education, stigmatised and living in poverty were less likely to have clear understanding of research. In addition, the study reported that willingness to participate is not dependant on understanding of the research.

Nuffield Council on Bioethics (2002) advises that research related to health should be sensitive to people's culture and practices of the societies being researched. The Nuffield Council of Bioethics states that researchers should not misuse their position of power by being insensitive to the way societies define themselves. This is also highlighted by Muthuswamy (2005) in her argument that since HIV and AIDS is laden with social, cultural and religious values, researchers should work collaboratively with community based organisations.

3.3.6.1 *Ethics and couple research*

Research with couples and families present unique ethical challenges some that are not completely covered by standard ethical guidelines (Margolin et al., 2005). This type of research involves more than one person. Therefore, in addition to individual ethical issues, there are ethical issues that concern the couple or family as a unit. Margolin et al. (2005) observe that the data in couple and family research are likely to intermingle. For instance, information provided by a woman can include some details that her husband might consider sensitive and private.

As discussed in section 3.3.4, constructivists maintain that research is value laden, and that it is impossible to ignore moral, cultural and political values (Walter, 2010). The world of couples is indeed laden with these values and deciding whether to interview together or separately has some ethical implications. When Morris (2001) suggested to couples that they should be interviewed separately, she observed signs of discomfort. The suggestion was construed to mean that there were secrets that the two partners had not shared and the researcher wanted to identify those.

Taylor and De Vocht (2011), while agreeing that world of a couple is co-constructed by the two partners, argue that interviewing them separately would not necessarily create anxiety. In their study, Taylor and De Vocht indicated in the consent form that information given by one partner will not be disclosed to the other. In addition, the study used follow-up interviews to explore after effects from the first interview. However, one would argue that the measures employed by Taylor and De Vocht (2011) is admission that interviewing couples separately can cause discomfort.

3.3.7 Subjectivity and reflexivity

Constructivists realise that subjectivity has a positive bearing of the relationship between the researcher and the participants, and that it contributes to the interpretation of data. As stated by Schwandt (2007) we use our historical and sociocultural dimensions to construct meaning in order to understand lived experience.

Phenomenologists believe that researchers are an integral part of the social world they seek to investigate (Denscombe, 2003). As such Denscombe contends that researchers use every day common sense assumptions to interpret phenomena. Therefore phenomenologists start their research by acknowledging their biases, presumptions, and beliefs. These are then suspended or bracketed through phenomenological reduction. However, Van Manen (1997) maintains that complete bracketing is impossible. In fact Giorgi (1994) posits that researcher subjectivity is not negative and efforts to eliminate it are misplaced in phenomenological research. Giorgi further argues that "[f]or phenomenology, nothing can be accomplished without subjectivity" (p. 205).

Following from the inevitability of subjectivity there is need for researchers to be reflexive in the conduct of social inquiry. In a methodological sense reflexivity concerns being aware of ones biases, prejudices, and theoretical predispositions. In general it involves critical examination of the research process including the way research establishes connection with participants to illuminate how this contribute toward data collection and interpretation (Schwandt, 2001).

Van Manen (1997) contends that phenomenological writing is a reflexive activity in which the embodied researcher describes what he or she is capable of seeing based on their interpretive framework of the world. However, Holloway and Biley (2011) warn that this may lead to self-absorption and gratification at the expense of the authenticity of research participants' experiences. To overcome these mishaps researchers need to be constantly aware of the context, purpose and focus of their study in order to minimize over-indulgence in their experiences (Doyle, 2012).

3.4   Qualitative and quantitative methodologies

This section will discuss the characteristics of qualitative and quantitative research. As stated by Creswell (2011) the dualistic division of quantitative and qualitative research methods does not hold in the practice of social research. Usually methodologists use the term "quantitative" in reference to numerical data, and "qualitative" in reference to textual data. However, Sandelowski, Knafl, and Voils (2009) assert that in practice, it is possible to assign numerical values to qualitative data so that they can be analysed statistically. Further, Sandelowski et al contend that the objective meaning of numerical values in standardised questionnaires is based on the subjective decisions of the researcher. Besides, Creswell (2007) notes that even the definition of qualitative research keeps evolving, signifying the ever-changing nature of qualitative inquiry. Therefore, this section will not attempt to draw a firm line between quantitative and qualitative research.

Quantitative research approaches are often associated with the collection of numerical data that are analysed statistically (Walter, 2010). Generally, quantitative researchers use a deductive approach, starting with a hypothesis from theory and collecting data to confirm or reject the hypothesis (Bryman, 2012). Besides, Creswell (2007) states that qualitative researchers that adopt the postpositivist doctrine will take a scientific approach to research. These researchers use logical steps similar to those used by quantitative researchers.

Quantitative researchers generally argue that research should be conducted in a value-free manner. However, quantitative researchers holding postpositivist views acknowledge that their

values can influence the way they conduct research (Teddlie and Tashakkori, 2009). Most quantitative researchers tend to be concerned with causal relationships between variables (Bryman, 2012), and ability to make generalizations (Lincoln et al., 2011). To achieve this quantitative researchers use probability sampling, mathematical modelling and statistical analyses (Bryman, 2012; Lincoln et al., 2011).

Creswell (2003) defines qualitative research as a means of exploring the meaning people attach to social phenomena. It is a "situated activity that locates the observer in the field" (Denzin and Lincoln, 2011b, p. 3). Qualitative research usually uses the inductive approach, beginning with a worldview and ending with data analysis that shows patterns or themes (Creswell, 2007). Some of the methodological approaches used in qualitative research are phenomenology, ethnography, phenomenography, case study and grounded theory.

Qualitative inquiry is conducted in natural settings where social phenomena are studied and interpreted in terms of meanings people bring to them (Denzin and Lincoln, 2011a). To this end, qualitative researchers stay as close as possible to the participants being studied (Creswell, 2007) in order to see them in action (Denzin and Lincoln, 2011a). Qualitative researchers aim to develop and describe the whole picture of the issue under study (Creswell, 2007). Creswell further states that a qualitative researcher writes in persuasive manner to enable the reader to experience the phenomena as if they were there. This kind of description of the social world is considered a valuable characteristic of qualitative research (Lincoln et al., 2011).

Justifying the appropriateness of qualitative methods, Flick (2009) argues that due to their complexity some phenomena cannot be studied in isolation. Therefore, Flick says, the phenomenon under study should be the determining factor for choosing a particular research approach and not the other way round. In addition, Allwood (2012) argues that the choice between a qualitative and quantitative research approach should be based on the specific research context, including the research question, and not on a general abstract comparison.

3.5   Research approaches

In the early stages of conceptualizing this study three research approaches were considered for use. Considering that the study would require entering the *life-world* of others, only approaches that would allow me achieve that in an empathic way were considered. *Life-world* is an "intersubjective world of human experience and social action; it is a world of common-sense knowledge of everyday life. It is constituted by the thoughts and acts of individuals and the social expressions of those thoughts and acts " Schwandt (2001, p. 147). The specific elements that

were critical in the choice of the research approach were the ability to allow empathic interaction with serodiscordant couples and allow them to describe how they experience HIV and AIDS information. Empathic interaction is to emotionally get inside the heads of others to understand their motives, desires and thoughts (Schwandt, 2000). These elements were considered in order to gather data that will answer the research question.

3.5.1   Phenomenology

Since this is the methodology chosen for this study, it will be discussed in more detail. The section will start with discussion of the definition and types of phenomenology. Further the section will outline the process of a phenomenological approach. The section will conclude by presenting the suitability of phenomenology to studying how serodiscordant couples experience HIV and AIDS information.

Phenomenology is widely associated with the philosophy of Edmund Husserl (1859 and 1938) who criticized psychology for applying scientific methods to studying human issues (Hammond, Howarth, and Keat, 1991; Laverty, 2003). The work was taken further by Martin Heidegger and he described the basic structures of the *life-world* (Benner, 1994). However, Heidegger's work was a departure from Husserl's transcendental phenomenology. Heidegger criticized the mind-body dichotomy view of consciousness and subjectivity, including how perception presents things around us, as advanced by Husserl (Benner, 1994).

In phenomenology the researcher seeks to understand how people experience a particular phenomenon and is not concerned with explaining the causes of phenomena. The aim is to gain a deeper understanding of the nature or meaning of everyday experiences (Van Manen, 1990). A phenomenon is anything that we know through our senses (Denscombe, 2003). However, "there are also phenomena such as believing, remembering, wishing, deciding and imagining things; feeling apprehensive, excited, or angry at things; judging and evaluating things; the experiences in one's bodily actions, such as lifting or pulling things" (Hammond et al., 1991). However, as argued by Benner (1994) it is important to address the question of what it means to be a person, the ontology, before considering the methods. Benner (1994 p.47) states that Heidegger's ontological perspective was that "the world is constitutive in that the self is raised up in the world and shaped by it in the process that is … non reflective taking up of the meanings, linguistic skills, cultural practices, and family traditions by which we become persons..."

Although there are many types of phenomenology, many commentators describe three types. These are hermeneutical phenomenology, transcendental phenomenology, and existential

phenomenology (L. Cohen, Manion, Morrison, and Bell, 2011; Creswell, 2007; Denscombe, 2003; Schwandt, 2001).

Transcendental phenomenology is closely associated with Husserl's concept of intentionality. Intentionality refers to being aware or conscious of something (Moustakas, 1994). The process of a transcendental phenomenological study described by Moustakas (1994) consists of three major steps; *epoché* or bracketing, transcendental phenomenological reduction, and imaginative variation. In the *epoché* or bracketing, the researcher's biases and assumptions are suspended in order to study the phenomena without these biases and assumptions (Schwandt, 2001). The researcher will then collect data from people who have experienced the phenomena. The transcendental phenomenological reduction involves looking at the phenomena "freshly, as if for the first time" and developing textural descriptions of the experiences of the people (Moustakas, 1994, p. 34). Imaginative variation is the process of deriving possible meanings from the experiences of the phenomena by varying the frames of reference and approaching the phenomena from different perspectives (Moustakas, 1994). Practically, Giorgi (1997) states that this is done by changing some aspects or parts of a phenomenon and checking if the phenomenon is still identifiable with that aspect or part changed. The result is a comprehensive description of human experience of a particular phenomenon (Moustakas, 1994)

Existential phenomenology rose from Martin Heidegger's critique of Husserl's transcendental phenomenology (Langdridge, 2007). Heidegger introduced the concept of "being-in-the-world" which "refers to how we make sense of the world, our place in it, and how we become aware of this place" (Klenke, 2008, p. 225). The objective of existentialism is to understand human condition in concrete and lived situations such as joy, happiness, and absurdity (Valle and King, 1978). Existential phenomenology focuses on the nature of existence, agrees with Husserl on the intentionality of human action but differs on "bracketing". Heidegger believed people exist in the world with an interdependent relationship with others (Klenke, 2008). Klenke further states that Heidegger viewed lived time as extending from past to present and therefore consciousness as historically lived experience. While agreeing that it was possible to set aside assumptions of the scientific approach, existential phenomenologists argued that they were "too practically engaged with the world …to be able to make such abstraction" (Langdridge, 2007, p. 25). Therefore, existential phenomenologists propose that we can bracket only some aspects of our assumptions and biases.

De Castro (2003) states that existential phenomenological inquiry has four characteristics. The first characteristic is that it is descriptive. The analysis and interpretations follow from the naïve

descriptions of the experience given by the research participants without the researcher's imposition of theoretical interpretations. The second characteristic is reduction, where the analysis draws meaning of an experience from what was presented. The third characteristic is the search for essence, in which the researcher looks for dominant characteristics of the phenomena. Finally, the fourth characteristic is the recognition that human actions are intentional.

Hermeneutical phenomenology is a methodological variant of phenomenology when it becomes interpretive rather than descriptive as in transcendental phenomenology (Van Manen, 2011). It is oriented towards lived experience (Creswell, 2003) and how people understand and engage with things in their life world, including themselves and others (Smith 2011). Historically hermeneutics referred to interpretation of biblical texts, and phenomenology became hermeneutical when Heidegger argued that human awareness is interpretive (Ehrich, 1999). The major proponents of hermeneutic phenomenology were Martin Heidegger and Hans-Georg Gadamer. While Heidegger viewed lived time (temporality) as extending from past to present, Gadamer viewed it as extending from present to future. In addition, Gadamer argued that understanding happens when one's horizons fuse with horizons of others. Horizon "is the range of vision which can be seen from a particular viewpoint" (Klenke, 2008, pp. 225-226)

M. Z. Cohen, Kahn, and Steeves (2000) isolated three constructivist assumptions as being important to hermeneutic phenomenological research. These are: the theory that there is no single reality, the importance of reflexivity and context in explanation, and that theory should be based on interpretations as opposed to description.

In hermeneutical phenomenology, the researcher engages in a process of self-reflection with a different purpose. The researcher's biases and assumptions are not 'bracketed' away but instead they are acknowledged and embedded in the interpretive process. Throughout the research process, hermeneutic phenomenologists are required to acknowledge their own experiences and the way in which their position and experience relates to the issues being researched (Laverty 2003).

One aspect of phenomenology that needs special mention is the natural attitude which is central to the idea of bracketing. The natural attitude is the everyday attitude that takes the world as given. Solomon (1980 p. 112) states that the natural attitude is the everyday view we have of the world where we just find ourselves in it and "takes it as it gives itself to [us] as something that exists out there". Husserl suggests that to deal with the natural attitude it is necessary to bracket or suspend the conventional opinions about phenomena, the scientific knowledge accrued over time, and all theorising (Moran, 2000). Moran suggests that this ensures that the researcher

avoids "misconstructions and impositions placed on experience in advance, whether these are drawn from religious or cultural traditions, from everyday common sense, or, indeed, from science itself".

3.5.1.1 Summary

This section has presented a description of the three dominant types of phenomenology. While all three types of phenomenology accept the intentionality of consciousness, transcendental and existential phenomenology emphasise description of human experience. On the other hand, hermeneutic phenomenologists use an interpretive approach to the study of human experience.

The three types of phenomenology also differ on *bracketing*. In transcendental phenomenology, Husserl proposes total bracketing of the researcher's presuppositions, assumptions and biases in order to see the phenomena as it is. The development of existential and hermeneutic phenomenology was a direct opposition to this belief.

This study adopted a hermeneutic approach. As stated by Van Manen (1997) any description of experience is itself interpretive. Therefore using hermeneutic phenomenology assisted me to interpret the descriptions of the experience of HIV and AIDS information that were provided by serodiscordant couples. Hermeneutic phenomenology was also chosen because of its resonance with the constructivist paradigm. Annells (1996) observes that hermeneutic phenomenology subscribes to a relativist ontological stance and subjectivist stance.

3.5.2 Other research approaches considered

Among the other research approaches considered was ethnography. Ethnography has its origins in cultural anthropology conducted by early 20th century anthropologists (Creswell, 2007). However, over the years the definition of ethnography has been controversial. Some researchers refer to ethnography as a research paradigm while others as a method one uses as and when appropriate (Hammersley and Atkinson, 2007; Silverman, 2011). Ethnography in its original meaning is a research methodology that uses direct observation (Silverman, 2011). It refers to the process, field work, and the product, written text (Schwandt, 2001). Silverman states that the presence of the researcher in the field in ethnographic studies gives them an opportunity to get a deeper understanding of the categories of social actors and the meaning they attach to their actions. Ethnography seeks "to represent in detail specific cultural contexts" (Jones, 2010, p. 26).

Ethnography is similar to phenomenology in that both approaches study human behaviour in their natural contexts. In addition, both use unstructured data collection methods to avoid imposing meaning on what people do or say (Hammersley and Atkinson, 2007).

Other studies of information behaviour have used ethnography. Examples are the study of the information world of HIV positive gay men in the UK (Minion, 2010) and the information behaviour of health care teams in the USA (Reddy and Jansen 2006).

Ethnography and phenomenology differ in the type of problems they are best suited to investigating. According to Creswell (2007) ethnography is suitable for holistic description and interpretation of shared culture while phenomenology is good for investigating the experiencing of phenomena. Considering that this study is focused on how serodiscordant couples experience one phenomenon, HIV and AIDS information, ethnography was found to be less appropriate. Specifically, ethnography was rejected because of its focus on holistic description of culture while the study will focus on experience of one phenomenon.

Similarly, phenomenography was considered. Phenomenography is similar to phenomenology in that they both aim at revealing how human beings experience social phenomena. However, phenomenography seeks to find "the qualitatively different ways in which people experience, conceptualize, perceive, and understand various aspects of, and phenomena in, the world around them" (Marton, 1988, p. 144). Data collection and analysis in phenomenography are exploratory and interpretative, and analysis results in qualitatively distinct categories of conceptions (Svensson, 1997). Marton (1988) states that the contexts of the categories of conceptions are disregarded so that the categories can be useful in other contexts. In the present study, the context of the serodiscordant couples' descriptions of how they experience HIV and AIDS information illuminated the meaning of their actions. In addition, this study was aimed at identifying what is common among a group of people experiencing a phenomenon and not the variations of experience. On this basis, phenomenography was also found less appropriate.

3.6   Sampling and recruitment

Guest, Bunce, and Johnson (2006) contend that research that is not aimed at drawing statistical generalisations and is field oriented in nature should use non-probabilistic samples. According to M. Mason (2010) in addition to other factors that affect sample size in qualitative studies, researchers should generally use saturation as a guiding principle during their data collection. In a phenomenological study of women's experiences of postnatal depression, Williamson (2005) used data saturation to determine the sample size, and 12 women were interviewed. Similarly, Greene (2009) had anticipated that 10 or less interviews would provide sufficient data to investigate patients experience of cranial treatment and 5 interviews were conducted. On the other hand, Ashbaugh (2011), investigating instructional designers' perceptions of leadership, selected 6 people who had the highest number of years of experience with the phenomena.

Morse (2000) asserts that research designs where the unit of analysis is a family or a group, one interview returns more data and the sample size needs to be smaller. In addition, Morse argues that unstructured phenomenological interviews result in large amounts of data per interview and a smaller sample size.

3.7   Data collection

In phenomenology, data can include the researcher's personal reflections on the topic, and information gathered from research participants through in depth interviews. Interview data are collected from participants who have experienced the phenomena under study (Creswell, 2007). Smith, Flowers, and Larkin (2009) propose that for phenomenological PhD projects a sample of 8 participants is large enough to satisfy the demands at that level. Klenke (2008) suggests a sample size of 2 to 25 participants and Creswell (2007) recommends 5 to 25 individuals for phenomenological studies. Other authors (Bowen, 2008; Guest et al., 2006; M. Mason, 2010) recommend that the researcher should continue interviewing until data saturation is reached. Data saturation means that new participants will continually be interviewed until the data set is complete or nothing new is being added (Bowen, 2008). However, originally data saturation referred to the point where categories are fully accounted for, variability among them are explained and the relationships between them are tested and validated (J. Green and Thorogood, 2004). Although many researchers claim to have applied the concept of saturation to determine the sample size, they do not explain what saturation meant in the context of their study (Bowen, 2008; M. Mason, 2010; O'Reilly and Parker, 2012).

3.7.1   Phenomenological interview

Smith et al. (2009) define an interview as a conversation with a purpose between the researcher and the participant. The main subject of a phenomenological interview is the life world of the participant (Kvale, 1983). It is not possible to understand social reality without considering people's perceptions, knowledge, interpretations, views, experiences and interactions. A good and creative interview is a tool that can get people describe these to the researcher (J. Mason, 2012). Kvale (1983) emphasizes that in order to obtain meaningful data, the interviewer needs to be sensitive to the interpersonal interaction and the subject of the interview. He states that unless the interviewer has an "ear" for the subject of the interview, they would not know how to probe intensively into the meaning of the interviewee's descriptions.

3.7.1.1   Interviewing couples

Studies that have explored the experiences of couples have had to make decisions on whether to interview the couples together or individually (Allan, 1980; Taylor and De Vocht, 2011). Taylor

and De Vocht (2011) contend that couples can never have shared meanings and understandings of experience. They further argue that each partner's experience is based on previous and current relationships, and future possibilities. For Taylor and Vocht, combining individual and couple interviews is beneficial because it results in a broader picture of the phenomenon.

Allan (1980) states that the major benefit realized when couples are interviewed jointly is the interactional way in which they create their accounts. According to Allan the couples corroborate their accounts and remind each other of certain aspects of their experience together. The disadvantage of joint interviews is that there might be some information a person will not be willing to discuss in front of their spouse or partner (Allan, 1980).

3.7.1.2   *Translating interview data*

Considering that this study was conducted in Malawi where the national literacy rate is at 65% (Malawi Government, 2012b) it was proper to conduct the interviews in Chichewa, the national language. The data were to be translated into English, which is language acceptable at University of Sheffield (University of Sheffield, 2012). Regmi, Naidoo, and Pilkington (2010) advise that researchers transcribe and translate everything that is recorded in the interview. In addition, Weeks, Swerissen, and Belfrage (2007) state that when using the services of professional translators, researchers need to consider the content of the interview transcripts as some translators might not be familiar with all content. However, van Nes, Abma, Jonsson, and Deeg (2010) argue that researchers need to stay close to the data in the original language as long as possible so that meaning is not lost in the process of translation. Van Nes et al contend that subjective experience and language has a two way relationship. First, the research participants use language to express meaning, and secondly the participants and the researcher also use language to construct meaning. Therefore, van Nes et al. (2010) and Chen and Boore (2010) recommend that researchers should analyse the interview data in the original language and just translate parts of the findings that will be used as quotations.

3.7.2   Observation

Observation is a process where a researcher immerses himself or herself in a research site to experience people's activities first-hand (J. Mason, 2012). According to Van Manen (1997) observation is one way of collecting experiential materials in phenomenological research. Van Manen states that observations should be carried out cautiously, being as close as possible to the situation while constantly stepping back to reflect on meanings of what is observed.

When planning to observe the researcher needs to consider how permission to access the research setting will be obtained. In addition, the researcher needs to decide on his or her role

during observation; "on a continuum between complete participant and complete observer" (J. Mason, 2012, p. 92). Similarly, researchers need to be aware that people being observed have the capacity to understand the objectives of the research and can assist the researcher to formulate his/her research plan (Angrosino and Rosenberg, 2011).

3.7.3   Field notes and field diary

Observations that are made by researchers as part of data collection are recorded as field notes. These field notes should be written at the same time as the field work (Emerson, Fretz, and Shaw, 2001). Palmer (2010) advises that it is important to use significant keywords that will make recall of the events when writing detailed notes. He further states that researchers should write the full version of their notes while their memory of what they observed is fresh.

3.8   Phenomenological process

There are different approaches to phenomenological research. Three approaches proposed by Moustakas (1994), Van Manen (1990) and Moustakas (1994) modification of Van Kaam's approach will be compared in this section. I chose Moustakas (1994) modification of Van Kaam's approach because the steps are more detailed and clarified than Van Kaam's original version. The three approaches were chosen using three criteria. First, I considered proponents of phenomenology that are widely cited. Secondly, among those I considered ones that devised systematic steps that can be used to conduct phenomenological studies. Finally, I chose the Max Van Manen's approach because it is both descriptive and interpretive. Sanders (2003) and Creswell (2007) identify Max Van Manen, Adrian Van Kaam and Paul Francis Colaizzi as major proponents of phenomenology who also devised systematic procedures for conducting phenomenological studies.

Although Adrian Van Kaam's and Paul Francis Colaizzi's approaches were not chosen for use in this study, they contributed to my understanding of the phenomenological research process. The prescriptive description of step 2 (Reduction and elimination) of van Kaam's approach by Moustakas (1994) assisted me to understand better Van Manen's imaginative variation. Similarly, thematic analysis in this study was informed by Colaizzi's step 4 (Organising formulated meanings into clusters of themes). I will now describe the characteristics of the three approaches.

3.8.1   Van Manen's (1997) approach

Max Van Manen is one of the major proponents of hermeneutic phenomenology (Williamson, 2005). . The approach emerged from Van Manen's study of pedagogy. It emphasises the situatedness in the life-world and that it is impossible to understand the experiential reality of

human beings separate from their life-world (Van Manen 1997). Van Manen's approach has been used, for example, in nursing to investigate women's experiences of postnatal depression (Williamson, 2005), in medicine to investigate patients' experience of cranial treatment (Greene, 2009); and in education to probe instructional designers' perception of leadership (Ashbaugh, 2011). Since this is the approach chosen for the study it will be described in greater detail.

The approach proposed by Max Van Manen is both descriptive and interpretive, and has six research activities. These are:

Turning to the phenomenon which seriously interests us and commits us to the world

Phenomenological study involves questioning some aspect of human experience phenomenologically (Van Manen, 1984). It is always a project of someone: a real person, who, in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence (Van Manen, 1997). Practically, this is done through the identification of a phenomenon of interest and formulation of a research question (Williamson, 2005)

Van Manen (1984, p. 42) breaks this step into the following sub-steps;

- **Orienting to the phenomenon**

The starting point in a phenomenological study is to identify the phenomena that deeply interest the researcher. Phenomenology is concerned with the concreteness and nature of the experience of the phenomenon.

- **Formulating the phenomenological question**

To do phenomenological research is to ask "what is the nature of this lived experience" (Van Manen, 1997, p. 42). Van Manen states that throughout the subsequent stages the researcher should be mindful of the phenomenological question.

- **Explicating assumptions and pre-understandings**

Usually the phenomena investigated in phenomenological inquiries are well known. The researcher has assumptions, suppositions and pre-understandings about the phenomena to the extent that he or she begins to interpret the phenomena before considering the data at hand. Van Manen (1997) asserts that if these assumptions, suppositions and pre-understandings are bracketed away, they will continually come back to influence the interpretation. Van Manen

proposes that this knowledge about the phenomena should be made explicit and during the interpretation the researcher should demonstrate that it is shallow and concealing.

Investigating experience as we live it

The experience is investigated by the particular methods the researcher utilises to generate the descriptions of the experience. These could be interviews, observations and field notes. According to Van Manen (1984) this step involves exploration of the phenomenon, lived experience, and materials that have a bearing on the phenomenon in order to get a deeper understanding of the experience. Van Manen (1997, p. 53) contends that the meaning of the phenomenon being studied should not be considered "granted" or "given", the meaning should only come from the descriptions of those experiencing it..

Van Manen (1984, p. 42) outlines the different approaches to gathering experiential materials. Only approaches that will be used in this study are described;

• **Using personal experience as a starting-point**

The researcher describes his or her experience of similar phenomena. Van Manen (1997) asserts that the description assists the researcher to reflectively be aware of what it means to experience the phenomena.

• **Searching idiomatic phrases**

Idiomatic phrases are forms of expression used in a way that is distinctive to a particular language, dialect (Oxford University Press, 2000). According to Van Manen (1997) idiomatic phrases are created out of lived experience of a group of people. He further contends that phenomenological researchers need to be attentive to experiential significance of phrases.

• **Obtaining experiential descriptions from subjects**

Van Manen (1997) suggests that one way of collecting experiential descriptions from people is to ask them to write about their experiences (protocol writing). Experiential descriptions can also be collected by interviewing people to gather experiential narrative materials and close observation.

Reflecting on the essential themes which characterise the phenomenon

Phenomenological analysis involves identification of themes and structures of the experience. The themes are useful in guiding the description of the experience (Van Manen, 1984). The thematic analysis is done in the following steps (Van Manen, 1984, p. 42);

- **Uncovering or isolating thematic aspects in life-world descriptions**

In Van Manen's (1997) approach thematic statements are isolated or uncovered in three ways,

a. Wholistic or sententious approach: In this approach, the researcher looks at the whole text or interview transcript and come up with a phrase that capture the fundamental meaning of the text or interview transcript.

b. Selective or highlighting approach: In this approach the researcher reads the text or interview transcript and highlight phrases or sentences that are revealing about the phenomenon or the experience.

c. Detailed or line by line approach: In this approach the researcher reads each sentence or cluster of sentences and consider what they reveal about the phenomenon or the experience.

- **Composing linguistic transformations**

The researcher writes notes to describe the themes in a phenomenological language. This process utilises the researcher's interpretations using insights from Step 2 (etymological meanings of words and idiomatic phrases)

- **Determining essential themes**

Some themes arising from the analysis are not particular or essential to the phenomenon or the experience. Van Manen (1997) asserts that isolating the essential themes from the incidental themes helps the researcher to discover aspects that make the phenomenon what it is and without which the phenomenon cannot be. The essential themes can be identified by the process of *Imaginative Variation*. The researcher will ask: "is this phenomenon [or experience] still the same if we imaginatively change or delete this theme?", "does the phenomenon [or experience] without this theme lose its fundamental meaning?" (Van Manen, 1997, p. 107).

Describing the phenomenon through the art of writing and rewriting

This stage calls for a suspension of our accustomed way of hearing and listening to the authentic voice of the interviewee (Van Manen, 1984). Van Manen further states that a phenomenological description points to the original, and that the description is just an example.

Maintaining a strong and oriented relation to the phenomenon

Van Manen (1997) observes that phenomenological projects are demanding and as such researchers risk getting side-tracked. There is also possibility that a researcher can wander aimlessly away from the phenomenon of interest and engage in wishy-washy speculations about the phenomenon. To avoid this scenario, Van Manen recommends that the researcher should maintain a strong and oriented relation to the phenomenon of interest. In addition, Van Manen suggests that a strong and oriented relation to phenomenon can be achieved through rich description which unlocks its resistance to our fuller knowledge.

Balancing the research context by considering parts and whole

A phenomenological project aims to answer the question: what is this experience like? However, Van Manen (1997 p. 33) warns that in the pursuit of answers to this question, researchers can be caught in the "under-brush and fails to arrive at the clearings that give the text its revealing power". Therefore, a researcher needs to measure the overall design of the study against the role the parts will play in arriving at the final goal.

3.8.2   Moustakas (1994) modification Van Kaam's (1966) approach

Adrian van Kaam's approach emerged from his doctoral dissertation work in 1958 (von Eckartsberg, 1998). In addition, von Eckartsberg classifies van Kaam's approach as existential. The approach is descriptive and has a quantitative element in that data is counted. Hein and Austin (2001) observe that van Kaam's approach is similar to content analysis in many ways, therefore suggesting a postpositivist epistemological bias. The original approach had 12 steps. Moustakas (1994) modified the approach by reducing the steps to seven and these are presented in figure 3.1 and described in detail in appendix XIII.

3.8.3   Colaizzi's (1978) approach

Paul Francis Colaizzi's phenomenological approach is descriptive (Shosha, 2012). Colaizzi (1978) advises that a phenomenological investigation should start with acknowledgement by the researcher of their pre-suppositions, and those should be used in formulation of the study research questions. This approach has 6 steps which are presented in figure 3.1 and described in detail in appendix XIV.

Moustakas' (1994) Modification of Van Kaam's (1966) Approach	Van Manen's (1997) Approach	Colaizzi's (1978) Approach

Data Collection

	Turning to a phenomena which seriously interests us and commits us to the world	
	Investigating experience as we live it rather than as we conceptualize it	

First level analysis

Listing and preliminary grouping	Reflecting on the essential themes which characterise the phenomenon	
Reduction and elimination		Extracting significant statements
Clustering and thematizing the invariant constituents		Formulation of meanings
Final identification of the invariant constituents and themes by application: Validation		Organising formulated meanings into clusters of themes

Second level analysis

Using the relevant, validated invariant constituents and themes, construct for research participant an individual textural description	Describing the phenomenon through the art of writing and rewriting	Exhaustively describing the investigated phenomenon
Construct for each research participant an individual structural description of the experience based on the individual textural description and imaginative variation	Maintaining a strong and oriented relation to the phenomenon	Describing the fundamental structure of the phenomenon
	Balancing the research context by considering parts and whole	Returning to the participants
Construct for each research participant a textural-structural description of the meanings and essences of the experience, incorporating the invariant constituents and themes		

Figure 3.1: Comparison of three approaches to phenomenological process

74

3.9   Validation and verification of qualitative research

The findings of a social inquiry are said to be valid when they accurately represent the phenomenon that was studied and are backed by evidence (Schwandt, 2001). However, there has been debate among social scientists on whether there is need to have criteria to judge qualitative research or not, and which criteria are appropriate. Lincoln et al. (2011) state that the issue of criteria for judging qualitative research cannot be dismissed because in one way or the other the findings will have to be judged and validated for authenticity. However Bochner (2000) contends that it is impossible to have universal criteria considering the diversity of philosophies in social sciences.

Some qualitative methodologists have proposed that validation criteria for qualitative research should be specific to a worldview or paradigm (Bochner, 2000; Creswell, 2007; Whittemore, Chase, and Mandle, 2001). Guba and Lincoln (1994) and Denzin and Lincoln (2011a) assert that postpositivist research should be judged using the conventional criteria which include internal validity, external validity, reliability and objectivity. According to Bryman (2012), there is uneasiness with the simplistic application of validity and reliability criteria to qualitative research as it presupposes an objective reality. Guba and Lincoln (1994) and Denzin and Lincoln (2011a) propose two sets of criteria for the constructivist paradigm. The first set is trustworthiness criteria which comprise of credibility, transferability, dependability and confirmability.

Credibility in qualitative research is established through "prolonged engagement in the field, persistent observation, triangulation exercises" (Seale, 1999, p. 44) and by ensuring that interpretations are accurate (Gray, 2009). In addition, there being multiple realities, Bryman (2012) contends that it is the feasibility or credibility of an account of a particular reality a researcher arrives at that will make it acceptable.

Qualitative researchers are expected to produce rich and comprehensive descriptions of the phenomenon they are studying. Since the descriptions are context specific, the richness of the descriptions provides the basis for others to judge the transferability of the findings to other contexts (Bryman, 2012).

Similar to the reliability criteria in quantitative research, qualitative researchers are expected to demonstrate dependability by keeping complete records of their research trail (Bryman, 2012). This process, called "auditing" is part of being reflexive and being self-critical about the methodological process of how the research was done (Seale, 1999). The auditing process is also useful in establishing confirmability (Bryman, 2012; Seale, 1999). Confirmability is the

requirement that the researcher demonstrates methodological transparency, and that their personal biases and values have not influenced the research process and interpretations (Bryman, 2012).

According to Seale (2002), the trustworthiness criteria were contradictory to the ontological stance of constructivism. However, Lincoln and Guba (1985, p. 329) argue that the trustworthiness criteria are "open-ended; they can never be satisfied to such an extent that the trustworthiness of the inquiry could be labelled as unassailable". Thus a second set was added by Guba and Lincoln (1994) to make the criteria for the constructivist paradigm consistent with the relativist ontology associated with it (Seale, 2002).This second set is authenticity criteria comprising of fairness, ontological authenticity, educative authenticity, catalytic authenticity, tactical authenticity.

Seale (1999) states that authenticity criteria concern whether the researcher has represented multiple voices and viewpoints (fairness), and helped people being researched to understand their social reality (ontological). In addition, authenticity requires the researcher to assist the people being researched develop a better understanding of other people within the same social world (educative) (Bryman, 2012). Lastly, authenticity criteria establish whether the researcher has aroused the motivation for action in the people being researched (catalytic) and empowered them to act (tactical) (Seale, 1999). This could be achieved by the researcher being involved in training the participants in social actions (Lincoln et al., 2011).

Creswell (2007, p. 215) proposes that readers of phenomenological research need to ask;

- "Does the author convey an understanding of the philosophical tenets of phenomenology?
- "Does the author have a clear "phenomenon" to study that is articulated in a concise way?
- "Does the author use procedures of data analysis in phenomenology,…?
- "Does the author convey the overall essence of the experience of the participants? Does this essence include a description of the experience and the context in which it occurred?
- "Is the author reflexive throughout the study?"

This study jointly applied the criteria proposed by Creswell (2007) for phenomenology and the credibility, transferability, dependability, confirmability and authenticity proposed by Guba and Lincoln (1994).

3.10 Chapter conclusion: my philosophical stance

This study seeks to describe how serodiscordant couples experience HIV and AIDS information. As described in Chapter 2 and in this chapter, the couples' actions draw meaning from the

interactions they have with others in their social world. Drawing on Elfreda Chatman's theory of Life in the Round, the serodiscordant couples live in a small world where their actions are influenced by social roles, social norms and context (Chatman, 1999; Fulton, 2005). Fulton (2005, p. 80) defines social norms as "standards of acceptable behaviour in a given context". They define what is acceptable or not and provides the basis on which social action is shaped by popular opinion (Fulton, 2005). A Malawian couple's social world is co-constructed with marriage counsellors, clan leaders, religious leaders, villagers and many other significant personalities that enforce and protect social norms. Therefore, my view is that there cannot be one reality in the small world of the serodiscordant couples. To generate knowledge about the distinctive elements of how serodiscordant couples experience HIV and AIDS information one would need to talk to the couples and let them describe their experiences. Through interaction and dialogue with the serodiscordant couples knowledge about their social world would be created. Knowledge can also be generated by observing the serodiscordant couples interacting with others in their social world.

Studies conducted in Africa have indicated that the HIV and AIDS information is impacted by social, cultural and religious values (Albright and Kawooya, 2005b; Buseh, Glass, McElmurry, Mkhabela, and Sukati, 2002; Manda, 2007; Sliep, Poggenpoel, and Gmeiner, 2001). As such, it was impossible to ignore values in this study. In addition, I acknowledged my values and biases (see chapters 1 and 4).

Based on my ontological and epistemological stance, the study adopted a constructivist paradigm. This allowed me to "gain an understanding of how people interpret the world around them, and how this informs their action" (Henn, Weinstein, and Foard, 2009, p. 16). This was also noted by M. Reddy and Jansen (2008) in an ethnographic study of information behaviour of patient care teams in hospital settings.

Based on the literature reviewed in Chapter 2, I was convinced that there was not much published on information behaviour of serodiscordant couples in general, and in Malawi in particular. As such, there would have not been enough theory to inform a deductive approach. Besides, Gombachika et al. (2012) in her study of barriers to accessing reproductive health services among couples with HIV and AIDS noted that the research involved emotive, sensitive and personal topics. Peters, Jackson, and Rudge (2008) assert that if couples are given an opportunity to describe their experiences a range of issues can become apparent and give rise to research findings that contributes to the health and well-being of couples. Therefore it was appropriate for me to use qualitative methods.

To answer the research question I chose a research approach that allowed serodiscordant couples to describe how they experienced HIV and AIDS information. Wilson (2003, p. 449) argues that "if we wish to understand the world of the information user and his or her actions in settings where information is made available by one means or another, we need to have conceptual tools that have been designed to foster that understanding". Wilson further suggests that phenomenology offer such conceptual tools. A phenomenological approach assisted me to investigate the "underlying context of individual behaviour in order to locate the patterns of information seeking and use for HIV/AIDS information (Albright, 2007, p. 10).Therefore hermeneutic phenomenological interviews were used to allow serodiscordant couples describe how they experience HIV information.

Chapter 4

Research Design and methods

4.1 Introduction

This chapter describes the specific methods I used to recruit serodiscordant couples, collect data, and analyse the data. The chapter will also show how the project design and methods were informed by methodological considerations discussed in chapter 3. Section 4.2 is organised based on the hermeneutic phenomenological approach outlined by Van Manen (1997). I also discuss in section 4.2.2.2 my position as a researcher in the field and how serodiscordant couples viewed me.

4.2 Phenomenological research approach

Phenomenology was chosen as a research approach that would enable me to answer my research question. The hermeneutic phenomenological approach was identified as well suited to investigating how serodiscordant couples experience HIV and AIDS information in Malawi. Hermeneutic phenomenology provided the means to capture descriptions of how serodiscordant couples experience HIV and AIDS information, and interpret the descriptions. Specifically, the study used Van Manen's (1997) phenomenological approach. The approach has six steps which are described in chapter 3. Van Manen (1984) states that the steps are not in a sequential order and do not form a mechanist set of procedures. "In the actual research process one may work at various aspects intermittently or simultaneously" (Van Manen, 1997, p. 34). I will now describe how these steps were applied in my study.

4.2.1 Turning to the nature of lived experience

As stated by Van Manen (1997) phenomenological research is a project of someone who in their context makes sense of a certain aspect about human existence. Thus, my study is about serodiscordant couples who in their context were able to describe what experiencing HIV and AIDS information is like. Therefore, this step involved formulation of the research question, deciding on the study population, and sampling.

During the initial stages of my study I engaged in literature search and reading around the subject of my interest. The aim was to increase my understanding of current trends and issues in HIV and AIDS, and serodiscordance. This assisted me to formulate and refine my research question which is presented in chapter 3.

4.2.1.1 Study population

The population of interest was mutually disclosed serodiscordant couples. The 2010 Malawi Demographic and Health Survey (MDHS) has indicated that "knowledge of AIDS among women and men in Malawi is almost universal" (National Statistical Office (NSO) and ICF Macro, 2011). However the 2012 Malawi Government report to the Joint United Nations Programme on HIV/AIDS reported that universal awareness was not translated into behaviour change (Malawi Government, 2012a). Further, new evidence has shown that new HIV infections are highest among married or cohabiting serodiscordant couples (World Health Organization et al., 2011). This group is not included in most HIV and AIDS programmes.

4.2.1.2 Sampling

The sample was drawn from mutually disclosed serodiscordant couples attending HIV and AIDS support groups or ART clinics in Lilongwe and Dedza Districts in Malawi. By its conclusion my fieldwork resulted in a purposive sample of twenty-one couples and three individuals who had separated from their partners. Interviews were conducted between September and October 2013. The sample size of 45 participants (21 couples and 3 individuals) was determined using data saturation and consideration of some demographic factors. Demographic factors that were used to determine the sample size were residential location and level of education. However, only one serodiscordant couple with a partner with university level education could be identified. Several HIV and AIDS support group managers told me that serodiscordant couples who had university education were not willing to publicly disclose their HIV status, and therefore not willing to be interviewed. Organisations that had a good potential of having serodiscordant couples with university education willing to be interviewed did not allow me to recruit couples for my study.

At the beginning of data collection the plan was to interview both partners together as couples. However, in the early stages of recruitment of participants it was discovered that many couples that were serodiscordant separated. I recorded in my field notes:

> The manager told me that KASO had serodiscordant couples on their register and mostly women in these couples were HIV positive. Women tested HIV positive at the antenatal clinic, when the husbands tested negative the couples separated. There was no serodiscordant couple left.
>
> I decided to interview some individuals who had separated from their partners. (28th August 2013)

I decided to interview some partners that had separated from their spouses after one of them tested HIV positive. The aim of these interviews was to investigate how experiencing of HIV and AIDS information contributed to the break-up of the serodiscordant couples. Lewis and Nicholls (2014) advise that qualitative researchers should be open to the unexpected and investigate unanticipated issues as they emerge in the course of the study.

Table 4.1 below summarises the demographic characteristics of the sample.

Table 4.1: Demographic characteristics of the sample

Composition	Number
HIV status	
Couples	
• Male HIV positive-Female HIV negative	10
• Male HIV negative-Female HIV positive	11
Individual partners	
• HIV positive males	1
• HIV positive females	1
• HIV negative females	1
Age	
• 25-44	29
• 45-64	13
• 65+	3
Education	
• No formal education	9
• Primary school education	23
• Secondary school education	12
• University education	1

4.2.2 Investigating lived experience as we live it

This step concerns collecting lived experience materials through conversational interviewing and close observation among other methods (Van Manen, 1997). My study used in-depth interviews to invite serodiscordant couples to describe how they experienced HIV and AIDS information. At the end of each interview I asked the serodiscordant couples to show me any information object they had in their home.

4.2.2.1 Gaining entry and recruitment

In order to gain entry and access the serodiscordant couples I identified gate keepers who facilitated the recruitment process. The gatekeepers identified were:

• Managers of Non-governmental organisations

- Convenors of HIV and AIDS support groups

- Coordinators of Antiretroviral clinics

- Hospital Directors

The gatekeepers were contacted in writing and through personal visits. Non-governmental organisations working in the area of HIV and AIDS do not normally work directly with HIV infected people. Therefore managers of non-governmental organisations and coordinators of ART clinics provided access to HIV and AIDS support groups.

The gatekeepers made the first contact with serodiscordant couples and explained to them details about my study. Then the gatekeepers asked the couples to participate in my study. A list of serodiscordant couples who accepted to participate in the study was passed on to me, and I contacted those couples to arrange for the interview.

4.2.2.2   *Positioning myself in the field*

As part of my choices of data collection methods I decided to conduct interviews in the homes of the serodiscordant couples. Beyond methods, this decision was useful in gaining trust from the couples. It was a good way of managing the interviewer-interviewee power relations. In hindsight I see the effect of me arriving in a car at a neutral interview venue would have had on the power relations. Kvale (2006) argues that qualitative interviews are usually dominated by the interviewer who chooses the topic and the time, who also starts and ends the interview. Furthermore, Randall, Coast, Compaore, and Wandera (2011) observe that poor and illiterate people can get intimidated by an educated and well-dressed interviewer. My approach to interview the serodiscordant couples in their homes, and letting them to choose an alternative venue if they wished shifted the power relations in their favour. One interviewee remarked:

> *"My final words are just thanking you for coming to see us, and to encourage you to come again and see us, encourage us. If you do that we will live happily. You should visit us regularly to hear our problems"* (HIV+ Female partner, Couple #8).

The study information sheet stated that I am a PhD student. This turned out to be a source of confusion as when translated into the local language PhD was confused with medical doctor by some serodiscordant couples. As a result some couples expected that I would conduct home-based HIV tests. I explained to all serodiscordant couples that I was a student and a librarian by profession, studying for an advanced degree.

In serodiscordant couples' homes it was necessary to show cultural sensitivity in order to be trusted and be told stories about experiencing HIV and AIDS information. Some cultural issues though trivial to me were revered by serodiscordant couples. Probably the best examples are taking off my hat when meeting senior people, and not turning down offers of food. I recorded in my field notes:

> *...I was offered a bottle of coke but I declined...After the interview I thanked the couple for welcoming me into their home. The husband reprimanded me for turning down a drink they had offered me (29th September 2013).*

Although I managed to bracket off my previous experiences of HIV and AIDS, it was emotionally daunting to hear stories of two partners with different HIV statuses working to keep their marriages together. To prevent burning out I took time off after every two days to unwind and get ready for the next round of interviewing.

4.2.3 Piloting the interview guide

The interview guide was piloted with two serodiscordant couples. The piloting of the interview guide was important in order to check the structure and order of the questions (van Teijlingen and Hundley, 2002). The data from piloting the interview guide were used with the rest of the data in my study. As stated by van Teijlingen and Hundley (2002) data from pilot studies are not used in main studies because of concerns of contamination. However, van Teijlingen and Hundley add that contamination is not a big concern in qualitative studies and data from pilot studies can be used in main studies. Therefore, I decided to include the pilot interview data in the analysis with the rest of the data.

After piloting the interview guide two questions were found to be eliciting similar response and therefore one was deleted. In addition, the opening question was not open enough so as to invite description other than a yes/no response. This question was replaced with a general and open question. The pilot and final versions of the interview guide are presented in appendices III and IV respectively.

The piloting of the interview guide also foreshadowed the possible reactions of serodiscordant couples to sensitive questions. Specifically, in the second pilot interview I encountered a male HIV negative partner who was confrontational at the beginning. However, when I demonstrated to him that I considered him more knowledgeable than myself, and that what he was saying was valuable to me, he turned out to be one of the best respondents.

4.2.4   In-depth interviews

In-depth interviews were the main data collection method. Serodiscordant couples were given freedom to choose the place, date and time of the interview. For all couple interviews both partners were interviewed together. This ensured that partners did not experience discomfort that their spouses were disclosing information they considered too private (Margolin et al., 2005). In addition, during the initial recruitment contacts with the gatekeepers it was clear that most couples would not commit to being interviewed for longer than 90 minutes because of work commitments.

All interviews, except one where the couple did not consent, were audio recorded. For the couple that did not consent to audio recording I took notes during the interview. All interviews were conducted in Chichewa, Malawi's national language. All interviews were conducted in the homes of the respondents.

Data collection started in Lilongwe City in Malawi. Couples were recruited from HIV and AIDS support groups in the city. Data were collected in three sites in the city. After each interviewing session I listened to the recorded interview to identify emerging themes. After seven interviews from the first three HIV and AIDS support organisations it was noted that no new themes were being mentioned. I then decided to recruit more couples from the other side of Lilongwe City in order to see if this different context would bring about new themes. True to my expectation new themes started emerging again. After eight interviews in this new location no new themes were mentioned. At this point I decided to explore the possibility of new themes from rural area context. Thus, nine more interviews were conducted in three sites in Dedza District. However, only one new theme emerged in the first of the nine interviews. Therefore, I took this as an indication that I had reached data saturation.

4.2.4.1   Phenomenological interview

The following is a description of interview meetings with serodiscordant couples. Upon entering the home I spent the first 5 minutes discussing casual issues such as weather and in the case of rural areas, farming. This assisted in establishing a sense of rapport.

The interviews commenced with confirming with each partner that they had strength to be interviewed. Throughout the data collection process no interview failed as a result of poor health. One interview was rescheduled because the male partner was drunk.

The next step was to explain details of the study to the couples. For couples that were literate the two partners were given the information sheet to read. Some couples were illiterate and I read the

information sheet to them. After reading the couples were asked if there were issues they needed clarification on, or if they had any question. I answered all questions the couple had and then together completed the consent form.

Generally, I started by asking the couple to describe their lives as serodiscordant couple. This allowed me to explore spontaneous topics in addition to what I had anticipated through the interview guide. I then moved forward by introducing topics on my interview guide and using probing questions to seek clarifications and open up the interview. Although most couples were able tell their stories freely, some needed patience and considerable prompting. In other serodiscordant couples one partner was more open than the other. I had anticipated this pattern before starting my fieldwork and I dealt with it by continuously prompting the quieter partner to speak while being careful not to completely shut up the other partner.

 I closed the interview when the two partners had exhausted their stories and I had no more topics to be discussed. At this point I asked the couple if they had information objects in their possession in the home. Most couples were pleased that I visited them in their home and discussed their HIV infection.

4.2.5   Observation and photography

As discussed in section 4.2.4.1, at the end of each interview I asked the serodiscordant couple to show me information objects they had in their possession. Usually at this point I had developed good rapport with the couple and they would bring out leaflets, newsletters, books, and some handwritten notes. On one occasion a couple took me to their kitchen, a small grass thatched hut, where they had left some HIV and AIDS booklets. The booklets were damaged by smoke and soot.

I used a camera to capture images of print information objects. For audio objects such as songs I took the details of the object and purchased a copy from music stores. Examples of photographs taken are presented in Appendix X.

In most cases, the information objects brought out by the couples resulted in a discussion and I would ask the couple for permission to record it.

4.2.6   Field notes

All events of my study were recorded in a notebook as field notes. Everyday field notes were recorded in two stages. While in the field I wrote short notes in form of points as reminders of events and important things that took place. At the end of the day I wrote the detailed notes.

In the field notes I recorded brief minutes of meetings with managers of HIV and AIDS management centres, support groups, ART clinics, and VCT centres. These were face to face or telephone conversations. I also recorded contact details for the couples. I took much care not to record confidential information in a manner that directly linked them to contact details.

4.2.7   Reflecting on essential themes

Van Manen (1997) states that phenomenological research concerns bringing to the fore that which eludes the eye because of the natural attitude. This was done by first listening to the recorded interviews. I then transcribed verbatim all interviews. I translated two interviews into English that were used for my training in qualitative data analysis with my PhD supervisors. The translated interviews were checked by a language expert from University of Malawi's Centre for Language Studies for correctness of the translation. The interview transcripts were coded using NVivo, qualitative data analysis software (version 10). The coding was done while the transcripts were in the local language. Figure 4.1 shows a screen capture of the coding window in NVivo.
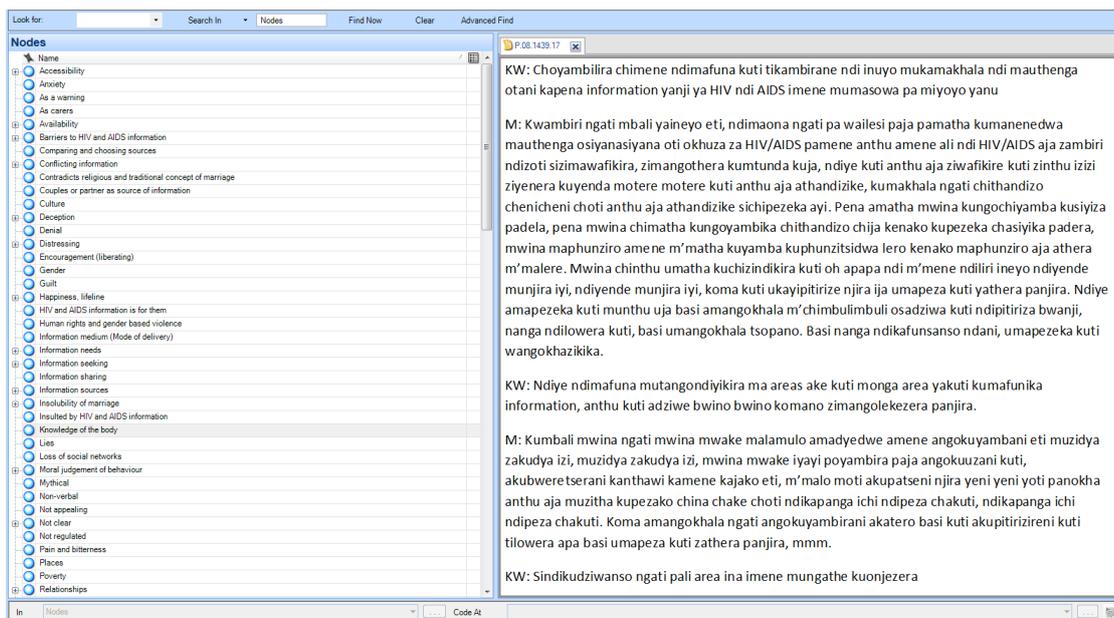
Figure 4.1: NVivo coding window

While coding, I was constantly comparing each interview to previously coded text to see if they were relevant to descriptions by the same or other serodiscordant couple (Bowen, 2008; Glaser and Strauss, 1999). I coded the interviews starting with no pre-specified codes. However, I used some insights from literature reviewed in chapter 2 to come up with themes. The coding was iterative because some issues that were not considered as substantive at the beginning of the coding came to be codes as the analysis progressed. In order, to ensure consistence in my coding, I included a description for each code I created.

The codes were analysed further to come up with second order categories. For this analysis I exported the codes from NVivo to Microsoft Excel (see Table 4.2) and printed the codes on small cards. A full list of codes imported from NVivo to Microsoft Excel is in Appendix VI.

Table 4.2: Codes imported from NVivo

		Code	Sources	References	Description
1		Code	Sources	References	Description
2	1	Accessibility	2	2	Information is in inaccessible formats or language
3	2	Anxiety	7	12	HIV and AIDS information making couples anxious or triggers anxiety
4	3	As a warning	2	3	Couples experience HIV and AIDS information as a warning of the dangers of sexual behaviours
5	4	As carers	6	9	Couples or partners experience information as carers of their spouses or their children
6	5	Availability	8	17	Availability or non availability of HIV and AIDS information for serodiscordant couples
7	6	Inadequate	3	9	Though available, HIV and AIDS is found to be inadequate or superficial
8	7	Barriers to HIV and AIDS information	5	5	Factors or things or practices that prevent couples from accessing HIV and AIDS information they know is available
9	8	Insiders and outsiders	2	5	Some HIV and AIDS information sources reject HIV negative partners
10	9	Comparing and choosing sources	4	7	Couples compare information sources in terms of trustworthiness
11	10	Conflicting information	5	7	Information conflict between sources
12	11	Some information is divisive	1	2	some information, especially from informal sources is aimed at breaking up couples
13	12	Couples or partner as source of information	10	20	Some couples or individual partners had desire to be or were sources of HIV and AIDS information
14	13	Culture	10	20	HIV and AIDS information is measured against culture; and messages that perpetuated by culture; couples made sense of HIV and AIDS information based on culture

As shown in figure 4.2, the codes printed on cards were grouped according to similarities and relationships. Codes (cards) that were related were placed in one envelope and each envelope was labelled with a thematic statement.
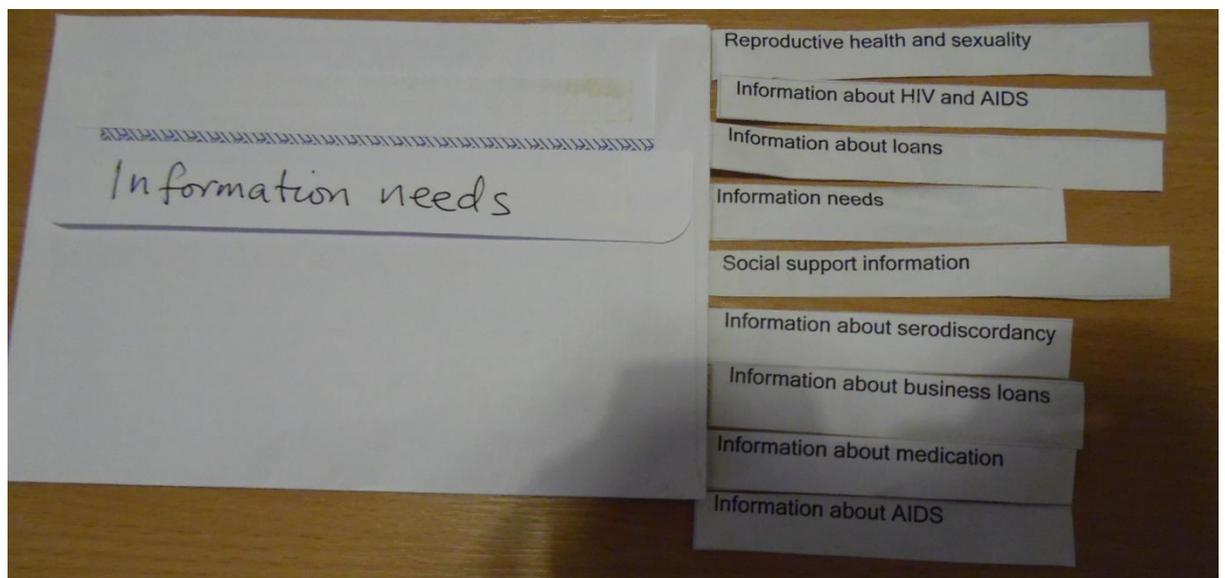
Figure 4.2: Thematic analysis using envelopes

More examples of how I developed the themes are presented in Appendix XI. Then a third order category was created by considering similarities among the envelopes. The resultant categories are presented in Table 4.2 below. A complete table of all categories is presented in Appendix XII. The process I used is consistent with what Van Manen (1997) proposes, that when coming up

with themes one has to look for commonality in the descriptions and identify statements that stand out.

Table 4.2: Categories developed in the thematic analysis

1st Order Category (Codes)	2nd order category (Themes)	3rd Order category
Pain and bitterness	Negative emotions	**Psychological aspects**
Disappointment		
Fear, threatening		
Distressing		
Anxiety		
Happiness, lifeline	Positive emotions	
Encouraging, liberating		
Happiness/lifeline	Denial	
Distressing		
Anxiety	Uncertainty and despondency	
Fear of separation		
Silence		
Inadequate information		

4.2.7.1   Free imaginative variation

In a phenomenological project the themes are considered the structures of the experience (Van Manen, 1997). However, Van Manen argues that some themes may not be unique to the phenomena of interest. Therefore, I applied the process of free imaginative variation on the themes in order to identify those that were essential and unique to experiencing HIV and AIDS information. This process was done by picking one theme at a time and asking the question; "is [the experience of HIV and AIDS information] still the same if [I] imaginatively change or delete this theme…?" (Van Manen, 1997, p. 107). If the answer was, yes, the theme was deleted or changed or merged with another. The result was that two themes were identified as incidental and deleted. Four themes, though essential were modified by merging them with other essential themes. One theme, Small world experience of HIV and AIDS information, was identified as essential and cross-cutting all the other themes. However, the theme was modified to 'life-world' with four sub-themes; 'lived body', 'lived others', 'lived space', and 'lived time'. The process of free imaginative variation is documented in appendix VII.

As the analysis was developing there was one aspect of experiencing HIV and AIDS information described by serodiscordant couples that was not adequately accounted for by the themes I had developed. Serodiscordant couples described their beliefs in God, and their relations with ancestral spirits. The initial thought to include these under religion came out not to be plausible as God and ancestral spirits had persona in the descriptions. On the other hand, these could also not fit in the 'life-world' theme as God and ancestral spirits did not exist in bodily form. At this point a new sub-theme, spirituality, was introduced in 'life-world' theme. As will be noted in Chapter 8, this came out to be a fifth existential of the life-world of serodiscordant couples.

4.2.7.2 *Interpretation of the themes*

After the themes were established I engaged in an iterative process of interpreting the themes in order to arrive at a rich description of how HIV and AIDS information was experienced by serodiscordant couples. I used hermeneutic conversations proposed by Van Manen (1997). These conversations were conducted with my supervisors in weekly meetings and in research group meetings. For the first of the hermeneutic conversations I produced thematic descriptions, which were essentially paragraphs in which themes from the data analysis were re-written in phenomenologically sensitive language.

4.2.8 Data analysis: a worked example

In this section I will provide an example of how data analysis was done from coding to the final theme. This example demonstrates how the 'life-world' theme emerged from the data. Figures 4.3 to 4.6 are screen captures of codes in NVivo, qualitative data analysis software.
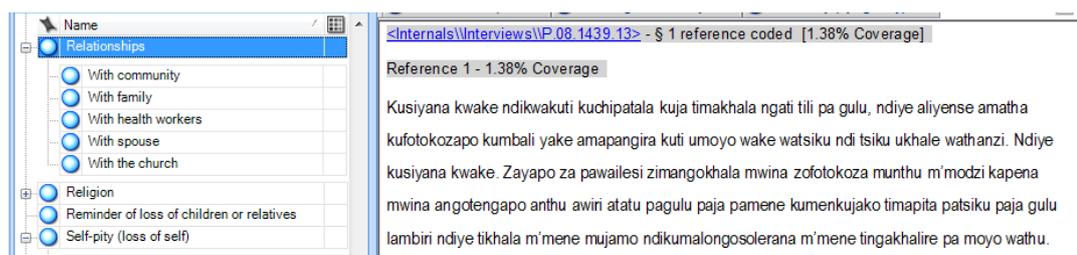
Figure 4.3: 'Relationships' code

During the early stages of data analysis the 'Relationships' code, presented in Figure 4.3, was grouped with other codes under an emerging theme called 'Intersubjectivity'. The rationale for this interpretation was serodiscordant couples'descriptions which suggested that HIV and AIDS information was experienced with other people, and meaning of the information was co-created.
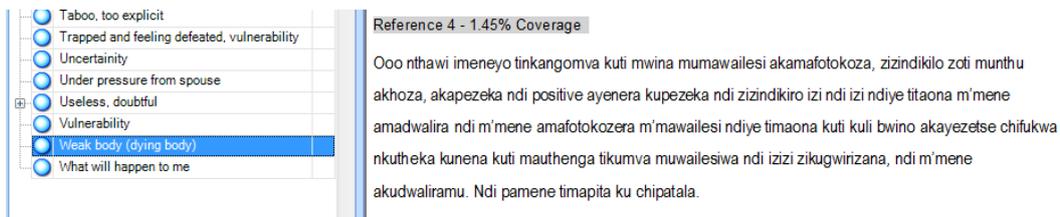
Figure 4.4: 'Weak body/dying body' code

My interpretation of interview excerpts that were coded under the 'Weak body/dying body' code was that partners in serodiscordant couples were referring to themselves. Therefore, I created a theme called 'selfhood'.
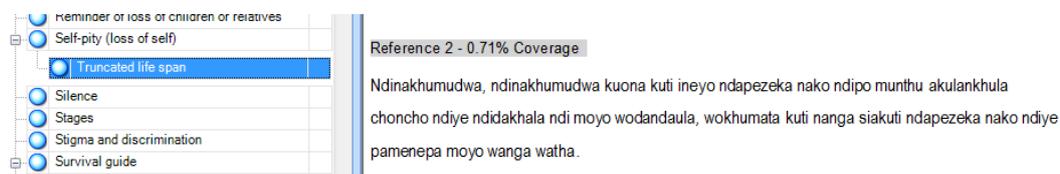
Figure 4.5: 'Truncated life-span' code

During the early stages of data analysis, the interview excerpts coded under 'Truncated life-span' code (Figure 4.5) gave me the impression that serodiscordant couples were describing their uncertainty about the future. Therefore, I included this code under the 'uncertainty' theme.
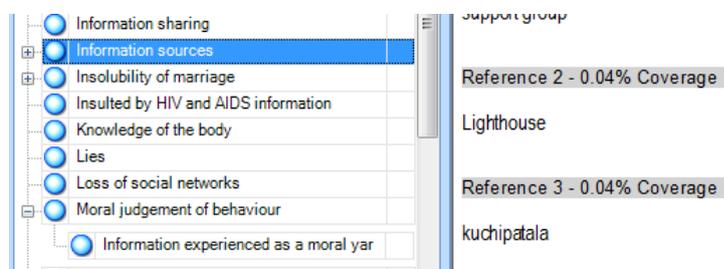
Figure 4.6: 'Information sources' code

During the coding of the interview data, there was an overlap between 'information sources' and 'places' codes. As the data analysis progressed the two codes were merged into one theme called 'places'. However, the 'information sources' code was re-introduced when I started writing up the results.

When the initial themes had emerged, it became necessary to trace the etymological definitions of the concepts 'intersubjectivity', 'self-hood', and 'uncertainty' as part of the interpretation of the results. The aim was to ensure that the use of these concepts in my study is consistent with the definitions. This led me to read books by Zahavi (2005) titled *Subjectivity and selfhood :*

investigating the first-person perspective, Howson (2004) titled *The Body in Society: An Introduction*, and Van Manen (1997) titled *Researching lived experience*. Insights from these readings illuminated flaws in my interpretations. At this point I introduced a theme called 'lived world experience' based on Van Manen's (1997) discussion of lived experience. As shown in Table 4.3, 'intersubjectivity' theme was down-graded to a sub-theme, and re-named 'lived body'. Similarly, 'selfhood' and 'places' were down-graded to be sub-themes, and renamed 'lived body' and 'lived spaces' respectively. For the 'uncertainty' theme, only codes that were referring to time were copied to the 'lived time' theme. However, the 'uncertainty' theme remained.

Table 4.3: 'Life world experience' theme and subthemes

Theme	Sub-themes	NVivo code
Life world experience	Lived body	Weak body/dying body
	Lived space	Information sources
	Lived time	Truncated life span
	Lived relations	Relationships

The next step in my data analysis was to identify similarities among the themes in order to come up with higher order categories as presented in appendix XII. At this point I realised that this theme was fitting into more than one higher order category. For instance, as lived bodies the two partners described experiences that entailed their social interactions with others which I categorised as sociological aspects of their experiences. They also described their emotions which I categorised as psychological aspects of their experiences. Furthermore, serodiscordant couples described themselves as sources of HIV and AIDS information. Therefore, I decided to elevate the 'life-world experience' theme into an overarching theme of experiencing HIV and AIDS information.

4.2.9 Phenomenological writing, and maintaining a strong and oriented relation to the phenomenon

The next two steps in Max Van Manen's phenomenological process are hermeneutic phenomenological writing, and maintaining a strong and oriented relation. These two steps were conducted through the process of writing. For my PhD project writing was an on-going process, from the design of the study, through data collection and analysis, to the end. The first phase of this process was done through proposal writing when I conceptualised and designed the study. Throughout field work I made notes in my research diary. The second phase of writing commenced when I started analysing the interview data. In fact, the writing process was part of the analysis because it assisted me to continually question whether my codes and themes were

true to serodiscordant couples' experience of HIV and AIDS information. Thus the writing process assisted me to maintain a strong and oriented relation with the phenomenon.

In writing I used quotations from what serodiscordant couples said about their experiences of HIV and AIDS information. The quotations were translated into English and a sample of the translated text was checked by a language specialist from University of Malawi's Centre for Language Studies.

4.3   Reflexivity

In phenomenology, the researcher is required to declare and acknowledge their preconceptions, inclinations and subjective feelings about the subject and bracket them. At the beginning of the data collection I wrote about my experience of HIV and AIDS. I acknowledged the effect HIV had on my life when some of my siblings were infected and lived in concordant couples. During the interviews I made an effort to overcome the effect of my subjective feelings and prejudgements on my questioning. I also guarded against these subjective feeling during the analysis and interpretation of the results.

Reflexivity was particularly important for my study because of the sensitivity of the topic I was investigating. In addition, serodiscordant couples, like other people living with HIV are a vulnerable group. I was reflexive in the procedures I used to recruit serodiscordant couples for my study. As outlined in section 4.2.2.1, all potential participants were contacted by managers of HIV and AIDS support groups or managers of VCT and ART clinics. I only met serodiscordant couples that agreed to participate in my study and never pursued those that declined.

However, as information professional I was inclined to correct misconceptions that did not require medical knowledge. On several occasions I advised serodiscordant couples about the reliable sources of HIV and AIDS information in their areas. In all cases I did this after the interview had closed to ensure that I did not influence their descriptions of experiencing HIV and AIDS information.

Throughout the PhD journey I kept a research diary. During fieldwork the diary entries included field notes and reflective logs (see Appendix IX).

4.4   Ethics and confidentiality

The study of the experience of HIV and AIDS information by serodiscordant couples was laden with many ethical issues. During the design of my research project I outlined a plan on how I would deal with the ethical issues. The plan was checked and approved in the United Kingdom

and in Malawi. Ethical approval from The University of Sheffield, Information School was received in August 2013 (see Appendix I) and from University of Malawi, College of Medicine Research and Ethics Committee (COMREC) in September 2013 (see Appendix II). The Malawi Government requires that all research conducted in Malawi should seek ethical approval in the country (National Research Council of Malawi, 2002).

Since there is stigma attached to HIV and AIDS in Malawi, it was necessary to ensure privacy and confidentiality of the participants. The participants were first contacted by managers of HIV and AIDS organisations or support groups. During the first contact with serodiscordant couples the managers of HIV and AIDS organisations or support groups asked the participants if they were comfortable to be interviewed in their homes, and procedures they preferred to be followed in order to ensure privacy and confidentiality. I only met serodiscordant couples that accepted to participate in the study. Although all couples agreed to the procedures the researcher had outlined on the information sheet during the first contact, these were also discussed with the couples before commencement of interviews.

I assured the couples in writing using the consent form, and verbally that their responses would be kept confidential and that they would not be identified in the report. Each partner in a serodiscordant couple was individually asked to consent to be interviewed and the interview being recorded. In addition, both partners were asked for consent to taking pictures of information objects in their home. Throughout the interviews I reminded couples of their right not to answer any question or end the interview at any point and withdraw their consent.

In the discussion before the interview, three couples raised ethics concerns that were successfully resolved and the interviews went ahead. The first couple asked me to explain how he came to know that the couple is serodiscordant. I explained the procedure that was being used to identify serodiscordant couples. The second couple was not comfortable with the requirement that they print their names on the consent form. They thought this was contrary to my assurance of anonymity. The couple was allowed to just append their signatures to the consent forms. The third ethical issue arose with a couple where one partner wanted their identity not to be protected. Considering that data in couple research can intermingle (Margolin et al., 2005), the couple was advised to keep their identities anonymous as one partner can say things the other partner might consider private and sensitive.

Three of the couples interviewed were illiterate and in one couple only one partner was illiterate. To obtain consent from these couples I read the information sheet to them and at the end they

were asked to say whether or not they agree to participate voluntarily. Their responses were recorded.

4.5   Validation procedures

As discussed in chapter 3 findings of social inquiry are valid when they accurately represent the phenomenon that was studied. I also discussed in chapter 3 proposed criteria for validating qualitative research, one of which proposes that researchers need to keep a complete record of their research trail. The outlining of the details of research design and its implementation demonstrates how key procedures were used to adhere to criteria for validation of qualitative research. This study used a phenomenological approach, and two sets of validation procedures were used. First, I applied the validation procedures proposed for phenomenological studies proposed by Creswell (2007). Creswell's criteria were operationalised as follows:

- Participation in the study was based on informed consent. I made effort to build trust with all participants by being open about my identity and the aims of my study. I also ensured privacy by interviewing them in their homes and assured all participants of confidentiality.
- Before embarking on my PhD project I read about phenomenology and in chapter 3 I conveyed an understanding of the philosophical tenets of phenomenology by discussing these in detail and applying these to my study.
- The phenomenon of interest in my study is articulated clearly in the research question and throughout this thesis.
- My analysis used Max Van Manen's approach to analysis of phenomenological data which are recognised data analysis procedures in phenomenology.

Secondly, I applied validation procedures proposed by Guba and Lincoln (1994). Guba and Lincoln's criteria were operationalised as follows:

- The fieldwork for my study was characterised by prolonged engagement in the field for a period of three months. This included persistent observation in the homes of the serodiscordant couples and in their communities.
- The description of how serodiscordant couples experienced HIV and AIDS are rich and comprehensive.
- Throughout this project I have been reflexive. For instance, I started by writing up my personal experience with HIV and AIDS (section 1.6.1), I read about reflexivity in qualitative research (section 3.3.7), and my discussion of the results also demonstrates reflexivity.

- An audit trail of this study is presented in appendices. These are data collection instruments, samples of raw data, sample of my field notes, and samples of the data analysis trail.

- Throughout the fieldwork I ensured that participants benefit from their involvement in the project by answering questions that were within my professional remit and recommending to them reliable sources of support.

- Dissemination of the study findings has already started.

4.6   Chapter conclusion

This chapter has documented the design process undertaken for this study. It has also outlined the methods and activities that were carried out in the recruitment of participants, data collection and analysis of the data. It went on to discuss the reflexivity, ethics and confidentiality issues that arose and how they were addressed. The chapter has concluded by presenting the validation procedures that were used.

Chapter 5

The life-world of serodiscordant couples

5.1   Introduction

This chapter presents the overarching framework of experiencing HIV and AIDS information for serodiscordant couples in Malawi. Earlier in this thesis (Chapter 2) the concept of life-world was introduced as the intersubjective region of reality where people play out their lives.

The results of this study reveal the four structures of the life world of serodiscordant couples. The four structures: lived body, lived space, lived time and lived others illuminate the experience of HIV and AIDS information and the meaning drawn therefrom. This chapter will also demonstrate how the four structures of the life world contributed to how HIV and AIDS information was experienced.

The analysis of interview data in this study identified the four structures of the life world as the overarching framework for experiencing HIV and AIDS information. These are important because first serodiscordant couples experience HIV and AIDS information in bodily form. In addition, all people the couples interacted with were met in bodily form. Secondly, serodiscordant couples were conscious of the space they occupied and described it as either welcoming or neglectful. Thirdly, couples described their sense of time, that which was seen to have been truncated by HIV infection. Lastly, the spaces occupied by serodiscordant couples were interpersonal spaces. Therefore, there were others that also occupied the same spaces as serodiscordant couples. As stated by Schutz and Luckmann (1973, p. 5):

> "The everyday reality of the life-world includes, therefore, not only the [phenomenon] experienced ... but also the social (and therefore the cultural) world in which I find myself; the life-world is not created out of the merely material objects and events which I encounter in my environment. Certainly these are together one component of my surrounding world; nevertheless, there also belong to this meaning-strata which transform natural things into cultural Objects, human bodies into fellow-men, and the movements of fellow-men into acts, gestures, and communications"

Therefore the life-world of serodiscordant couples will be described using the four structures as gleaned from the couples' descriptions of their experience of HIV and AIDS information. The discussion in this chapter is divided into five parts. The first four sections examine the four

structures of the life world. The discussion is drawing on the experiences of HIV and AIDS information by serodiscordant couples. The fifth section draws together the four life world structures to create a consolidated picture of the life world of serodiscordant couples. I will conclude by proposing a fifth life-world existential.

5.2   Corporeality (Lived body)

Serodiscordant couples that were interviewed were diagnosed between 2004 and 2013. All couples were living in their communities at the time of the interview. They were in the world in bodily form. They met and interact with others through their bodies (Van Manen, 1997). When in the world, public opinion of the individual partners was based on the appearance of their bodies.

In interview conversations serodiscordant couples described their views about their own bodies. Before diagnosis of the HIV infection some couples described the HIV positive partner's body as being in a state of physical decline, with many illnesses.

> *"At the beginning of all this, my friend was always ill, I was confused. At the hospital they always told us that they could not identify anything wrong with her. At the very beginning she was diagnosed with TB" (HIV- Male partner, Couple #13)*

The confusion referred to in this excerpt appears to arise from the expectation that bodies will at some point fall ill. In addition, when the illness is diagnosed expectations were that it will be treated. These expectations are captured in the description by the HIV positive partner in couple #20 of his illness before diagnosis of HIV infection.

> *When I look back I ask myself many questions. That time I was coughing, pain every part of my body, but that time I was not bothered because I thought it was just another illness, everyone fall ill at some point. I did not know what it was, I realised what it was when they tested my blood (HIV+ Male partner, Couple #20)*

Although the male partner's body showed signs and symptoms of HIV infection couple #20 did not suspect that it could be HIV. Most serodiscordant couples told me that they believed they were safe from HIV infection because they were in a stable marriage relationship.

After the diagnosis the HIV positive partners became conscious of the virus they were carrying in their bodies. After diagnosis most couples feared the immediate death of the HIV positive partner.

> *"...when I heard that he was positive I was distressed, I thought that maybe he would die anytime" (HIV- Female partner, Couple #1)*

On the other hand, immediately after the diagnosis of their spouses, HIV negative partners looked at their bodies as HIV infected even before going for VCT themselves. This view was influenced by HIV and AIDS information they had about HIV transmission. Immediately, after diagnosis of his wife, a husband in couple #19 believed he was the one who infected her.

"In my mind I had so many thoughts, they say that you can get infected with HIV when you are promiscuous, through promiscuity with many men or women, personally I started questioning myself; where did I get this AIDS? Because this one is not my first wife, my first wife was from Lilongwe. ... I was surprised when she was found HIV positive; I started suspecting that my first wife infected me" (HIV- Male partner, Couple #19).

Even after going for VCT and found HIV negative, some HIV negative partners still believed the virus was just hiding and that they were HIV positive.

"I still want to know, I still try to find out because I believe maybe it's just hiding, maybe I will be found HIV positive" (HIV- Female partner, Couple #16).

These examples suggest that, based on the mainstream HIV and AIDS information that states that HIV is transmitted through unprotected sex, HIV negative partners believed their bodies were infected. On the other hand, these examples signal lack of HIV and AIDS information on serodiscordance.

With the passage of time after diagnosis, some couples appeared to transition into another phase in which they began to look for means to mitigate against the effects of HIV on their body. They were wary of the possibility of the viral load increasing to fatal levels. For example an HIV positive partner whose husband was refusing to use condoms explained that:

"I was hurting inside; we were advised at the hospital to use condoms so that the virus in my body should not multiply, I should have few viruses. Because when you do it like that they will multiply. My heart was hurting because my friend was refusing" (HIV+ Female partner, Couple #14).

Similarly, another HIV positive partner, who was on separation from her husband at the time of the interview, feared that an increase in her viral load could lead to death. She got HIV and AIDS information from television which mentioned that unprotected sex can lead to increase in the viral load in people living with HIV. She said: "*this message threatened me; I thought that if I sleep with many men they will kill me; they will give me their viruses, the viruses will enter my body*" (HIV+ Female partner, Couple #10, separated)

For some serodiscordant couples the body was viewed as having a communicative function. It either concealed the HIV status:

"When you go to the health centres you are told that; 'we can't give you [nutritional flour] because you look healthy', they don't know that it's the CD4 count that explains the health status of one's body. He looks thin but he is HIV negative; I look plump yet I am HIV positive, who will require nutritional supplements?" (HIV+ Female Partner, Couple #3)

or revealed it:

"...then she went to The Lighthouse, when she was tested they said for you, because she had, what do you call that? [Female partner responds]: Candidiasis. Yes, she had those and she had severe diarrhoea, high fever. They told her that she should start treatment straight away" (HIV- Male partner, Couple #17)

In addition, serodiscordant couples used their bodies as a source of HIV and AIDS information. Couple #11 described how they used their bodies as a source of HIV and AIDS information for others. Personal biomedical information such as HIV test results and CD4 count were used to convince suspected HIV cases in their communities to go for VCT. The use of the HIV infected body as a source of HIV and AIDS information for others was evident in several conversations with couples. Couples that had lived with HIV for a long time and were still in good health used their bodies alongside their personal health information to convince others to go for VCT.

"First you look at the person, the way they look; I tell them; 'my friend, don't waste time, just go to the hospital. This also happened to me, even if you will be found to be [HIV] positive, I am also [HIV] positive'. That time I have my HIV status record and show them; 'see, I am on ART'. What you are doing here is why we hear of people dying. What you should do, just go for VCT, this is between you and me'. In most cases they come back with HIV positive results" (HIV+ Male partner, Couple #11)

Most serodiscordant couples demonstrated awareness of the signs of AIDS as manifested on an infected body. They talked about lesions and sores as conditions that indicate HIV infection. In the following excerpt a woman describes how she was advised to look out for signs on her husband's body in order to prevent HIV transmission:

"But when he has sores on his body and you want to bathe him, wear plastic bags in your hands. Never bathe him without plastic bags on your hands. Yeah, we were advised like that." (HIV- Female partner, Couple #21)

When couples were faced with unexplained illnesses they started seeking health information to answer their questions. Personal health information obtained from HIV testing centres made couples become conscious of their bodies. As a result, they needed more information about their bodies. One couple described how they were baffled by the HIV-like symptoms the wife was experiencing yet the husband, as a blood donor, had frequent HIV tests which came out negative.

> "So whenever I told her to go for testing she always said; why should I waste time when you as a blood donor are tested all the time, can you see that? Even myself, I thought it was enough" (HIV- Male partner, Couple #17).

After couples knew about their serodiscordance, HIV positive partners looked at their bodies as sick bodies. When HIV and AIDS information talks about the effect of HIV infection on the immune system, the HIV positive partner uses that information as a lens through which to look at their body.

HIV and AIDS information that described HIV as a killer made HIV positive partners conscious of a dying body.

> "I was gripped with fear, when I slept like this [sleeps on the mat] I could hear my heart pounding inside me, the pounding could be heard in the whole house dididi. When I wake up this house appeared too big for me, am I not dying tomorrow?" (HIV+ Female Partner, Couple #19).

On the other hand, the HIV negative partners, viewing their partners as dying bodies, feared for their expected physical decline and death especially where the HIV positive partner was the bread winner.

> "Now that this problem has befallen us, and we also have another problem, a blind child, are we able to support this blind child to finish school? Are we going to be alive until then? Our desire is to learn how to manage this new life, we should ask people like you can we live to care for our children until they grow, are we not dying today?" (HIV- Female partner, Couple #18)

On their part, the HIV negative partners consider themselves as vulnerable bodies. With HIV and AIDS information that states that HIV is sexually transmitted, HIV negative partners felt vulnerable when they had sexual contact with their HIV positive spouses. Some HIV negative partners reacted by separating from their spouses. Because of HIV infection the home became unsafe for the HIV negative partner.

"When this happened my wife became distressed and feeling that she can't stay with me in the same house as a married couple. When we came back we stayed although she started stigmatising me. When she prepared food, she used to eat alone, refusing to eat with me" (HIV+ Male partner, couple #6).

Evidence from the interviews suggests that couples who had lived with HIV for a long time reached a stage where they accepted the illness. In this stage couples described their bodies as being in good health. This was discussed in terms of efficacy of ART, absence of illness, and ability to carry out daily chores.

"...and there is no difference, we just live like other normal people. We just hear people talk about HIV; we set aside all our anxieties because we accepted that this is what we are and we will live with it. ....I am able to work in the garden without any problem" (HIV+ Male partner, Couple #11)

As married couples serodiscordant couples are expected to bear children. In addition, relatives and the larger society also expected them to bear children. Therefore, serodiscordant couples viewed their bodies as child-bearing bodies. Probably the best example is captured in the exchange between the two partners in couple #19:

Researcher: Now that your husband wants a baby and you insist on using condoms for fear of infecting him, what is the experience like?

Female partner (HIV+): My husband wants a baby? And he says we should not use condoms?

Researcher: Yes

Female partner (HIV+): We use condoms, that's all, after all I was sterilised so I can't conceive.

Male partner (HIV-): Reverse the sterilization, that can be reversed [laughs]

As such, serodiscordant couples needed HIV and AIDS information that could be used to assess the suitability of their bodies for child bearing.

"... there are so many issues, like the way I am, what changes can occur between me and my wife, what changes can occur or is it possible for her to bear children. Are there strange things that can happen on us? I need to know those things, I need to know, and those are the things I need to know" (HIV+ Male partner, Couple #6).

My analysis of data as presented in this section suggests that serodiscordant couples' first encounter with the HIV infection was through the lived body. In addition, most HIV negative partners self-diagnosed themselves as being HIV positive before they were tested. Serodiscordant couples also viewed the HIV positive partner as a dying body, and the HIV negative partner as a body vulnerable to HIV. Furthermore, serodiscordant couples used their bodies as a source of HIV and AIDS information.

5.3 Spatiality (Lived space)

During the interviews serodiscordant couples made reference to lived spaces they occupied as part of their experience of HIV and AIDS information.

Except for the three partners who had separated from their spouses, all partners in serodiscordant couples interviewed were living together in one house. The home was an important lived space, described by the HIV positive partner as either supportive:

> *"....like us, our home is happy, we never disappoint each other." (HIV+ Female partner, Couple #9)*

or neglectful:

> *".....my problem in this house is the constant fighting with my husband, he always confronts me; 'Where did you get this disease', and I always answer like I have explained to you....." (Couple #4)*

The home was also described as being 'too big' by a partner when describing the time she was newly diagnosed and anxious about being HIV positive.

> *"When I wake up this house appeared too big for me, am I not dying tomorrow?" (HIV+ Female Partner, Couple #19).*

This comment seems not to refer to the mathematical space but rather the experience of lived space. The home was experienced with feelings of smallness because of the HIV infection.

The epiphany of realising that their spouse is HIV positive created a sense of insecurity in the home. Some HIV negative partners told their spouses to *"go where you got [HIV]" (HIV- Male partner, Couple #14).* This resulted in most female HIV positive partners sent away from the matrimonial home;

> *"It reached a point when I chased her, I said 'woman pack your things and go' where did you get this thing, I look after myself well" (HIV- Male partner, Couple #14)*

On the other hand, some female HIV negative partners abandoned their matrimonial homes to run away from their HIV positive spouses. A female HIV negative partner in couple #6 started by refusing to sit at the same dinner table with her HIV positive husband.

"When we came back from [VCT] we stayed but I was discriminated. Sometimes, when she cooked food she would eat alone, away from me

.

.

Then it happened that when I went to work she packed all things and run away. When I came back I found she was gone" (HIV+ Male partner, Couple #6).

Evidence from observations that were conducted after the interviews suggests that the home was also viewed as a safe place to store HIV and AIDS information. HIV and AIDS information was kept in the couples' bedrooms. In the bedroom the information was stored in metal pots, plastic bags, handbags or on shelves. Metal pots and plastic bags were used to keep HIV and AIDS information that was in print format safe from termites and other insects that could destroy it. Examples of how HIV and AIDS information was stored are presented in Figs 5.1 to 5.3.

Figure 5.1: HIV and AIDS information stored in a hand bag

Figure 5.2: HIV and AIDS information stored in a plastic bag

Figure 5.3: HIV and AIDS information stored in a cooking pot

The home was also viewed as a space of hospitality. However, evidence from interview conversations indicates that serodiscordant couples felt stigmatised and rejected when other people refused to come into their homes.

"Sometimes people refuse to take our food, they refuse, we and our children. They make derogatory remarks about our illness, they say; 'the ill people's home' and we just say it's okay, we will live with our illness" (HIV- Female partner, Couple #22)

Serodiscordant couples also inhabited lived spaces such as the ART clinics, VCT centres, hospitals, and HIV and AIDS support groups. Couples' statements indicated that they were

comfortable at ART clinic, VCT centre, and HIV and AIDS support group where they were among other people living with HIV.

> *"....I get HIV and AIDS information from Bottom, because at Bottom when we go to get ARVs we freely interact with the nurses, we are able to ask them any question when you have one" (HIV+ Male partner, Couple #11)*

Besides, they believed that either personnel in these institutions were HIV positive or had specialised training in HIV and AIDS. Consequently, couples felt welcomed and free to seek HIV and AIDS information from personnel.

Some HIV negative partners experienced rejection in ART centres, VCT centres, and HIV and AIDS support groups. People that are HIV negative were considered as outsiders in these lived spaces.

> *"For instance I am positive and my husband is negative, if he accompanies me to the support group, people will say he has come to spy on us. He doesn't have the virus. They forget that we are a couple and we stay together in one house therefore he is affected by the problem I have. Instead of welcoming him at the support group they say he has come to spy on us, he should go, he is not one of us, they chase him away when he could have benefited, he could have gotten some information he would use at home. But they chase him" (HIV+ Female partner, Couple #17).*

Serodiscordant couples experienced rejection in some spaces in the communities where they live. The most frequent example of this rejection given by couples was being denied subsidised farm input coupons. The Malawi Government has a social support programme aimed at subsidizing farm inputs prices for the poor. Beneficiaries are given coupons that are used to buy farm inputs at subsidized prices. Couple #21 described their experience at their village chief's court:

> *"Then there came the issue of coupons; they said why did they contract the virus that causes AIDS, should you give coupons to the sick people? At first it was painful. But when I explained to the village chief what I had heard on the radio and from other HIV and AIDS organisations he understood" (HIV+ Male partner, Couple #21)*

My analysis of data as presented in this section suggests that the home was the primary lived space inhabited by serodiscordant couples. It was described as welcoming by some couples or neglectful by some HIV negative partners that were chased from the home by their spouses.

Other lived spaces such as HIV and AIDS support groups and village forums were shared. Some partners in serodiscordant couples faced rejection in these shared spaces.

5.4   Temporality (Lived time)

Although the serodiscordant couples were able to describe their experience of HIV and AIDS information in the past, evidence from interview conversations suggests that they were more concerned with lived time extending from present to future. Speaking of the past some couples said; "*zagwazatha*" *(it has happened and it is done)* (HIV- Male partner, Couple #11).

HIV is described as a life truncating illness. As such serodiscordant couples believed that their life span was truncated. Couple #20 cited HIV and AIDS information targeted at the youth which states that *"life is supposed to start from childhood and end in adulthood"* and they felt their "*right to live a long life is violated by HIV" (HIV- Female partner, Couple #20).*

As parents many couples expressed concerns about longevity of their lives and marriage. Serodiscordant couples that had children were worried about their possible death and that their children will not be cared for.

> *"Since we have children, it is good for me and my wife to use information we get from MACRO or on the radio. It will be a good thing for these children to have hope, they should have hope for the future" (HIV- Male partner, Couple #3)*

Further, serodiscordant couples that were expecting babies or were considering having babies were concerned about transmitting the virus to the unborn baby. Couples were worried that HIV infection will shorten the lifespan of their baby.

> *"For me this message is very important, and I like it very much. Because I was worried; 'Will I ever have a baby or if I give birth to, will the baby be health? In the end I will spoil my baby's future; it will not be healthy and may not live a long life, yeah" (HIV+ Female partner, Couple #14)*

For most HIV negative partners, the sense of being in a serodiscordant heterosexual relationship was associated with an uncertain future. These partners were told by VCT counsellors that their negative HIV status could have been as a result of "*the virus hiding*" (Couples #22 & #11). Further to that, they were told to go back for VCT to verify their HIV status. Although this information is effective in warning young people about HIV, for serodiscordant couples it was understood as implying that they would not reach old age, and that they would die soon.

A further reflection on lived time was revealed in the interview conversation with couple #3 when the HIV negative partner remarked that:

"When I hear HIV and AIDS messages the main point that lingers on my mind is thinking about my family, thinking about my life where it is going, what is the future like? And how should I look after myself so that I can live a longer life?"(HIV- Male partner, Couple #3)

Lived time was also expressed in terms of treatment for HIV. HIV positive partners were distressed about the thought that they will be on ART for the rest of their life.

"Some of these messages, for me it is something that distresses my heart. A life of taking medicine every day is so painful" (HIV+ Female partner, Couple #13)

HIV and AIDS information that states that people living with HIV should take ARVs for the rest of their lives triggered thoughts of a lived time that would be hard. An HIV positive partner who had heard this information before testing HIV positive states that the same information had a different meaning when reflected upon after testing HIV positive.

".... when I heard this information that when you are found with the virus you take medication the rest of your life I was touched. I first heard this information before I was positive and it did not touch me as much, but when I was found with the virus and reflected on this information I was greatly touched" (HIV+ Male partner, Couple #1)

Some serodiscordant couples interviewed in the study described lived time as extending from the past to present and into the future. Lived time in the past was described in terms of a period of illness that necessitated going for VCT:

"I was surprised with the coming of this illness because I had severe diarrhoea and mild malaria. With that illness I suggested to my husband that we go for HIV testing" (HIV+ Female partner, Couple #24)

Lived time that extends from past to present was also described in terms of the lives of children or siblings that were cut short because of HIV and AIDS. For instance, an HIV negative wife talked about her sister's death as a predictor of her lifespan.

"Look, just last year my sister died, living me with many orphaned children, what has happened is not good at all, my brother I am really distressed"

.

.

106

> *My mother is very old ... if we explain this to her she will be distressed, she will know that anytime from now I will also found HIV positive and die suddenly, then all the children will be left with her" (HIV- Female partner, Couple #18).*

The anticipation of future lived time was different for couples newly diagnosed as compared to those that had lived with HIV for some time. For example, a couple diagnosed in 2013 expected a bleak future and death from HIV and AIDS:

> *"I want to know about our life, the way we are that one is positive and negative. Are we going to live long to look after our children? We have children. How can we look after our children since my husband is positive and maybe he can die today" (HIV- Female partner, Couple #)*

while another couple diagnosed in 2007 viewed HIV as any other disease and anticipated long life.

> *"Can we say that all people that all people that will die from today to Monday will die of AIDS? No, we can also live a long life if we follow what doctors tell us and read the word of God" (HIV+ Male partner, Couple #11).*

On the other hand, evidence from interview conversations suggests that HIV positive partners had a more positive anticipation of future lived time. HIV negative partners expected sudden physical decline and death of their spouses. Some who believed that they were infected despite negative HIV test results talked about their death.

> *"...when I heard that he I was distressed, I thought that maybe he would die anytime, and if I am found [HIV] positive I would also die quickly" (HIV- Female partner, Couple #1).*

My data analysis as presented in this section suggests that lived time was experienced as being linear, extending from the past, to present, and into the future. In addition, lived time was experienced in relation to others, especially children. Couples believed that HIV would shorten their life span and they would not be able to look after the children. Lived time was also described as being problematic because of the routine of having to take ARVs several times a day for the rest of their lives.

5.5   Relationality (Lived others)

Physically the two partners in a serodiscordant relationship interacted with each other in a corporeal way (Van Manen, 1997). As primary care givers, HIV negative partners formed

impressions about an HIV infected body through manifestations of the illness on their spouse's body. As a couple, the two partners maintained links with their relatives through marriage advisors (Borne, 2005). Beyond their family or clan serodiscordant couples were also members of the village or town community. These communities had many institutions to which the couple belonged. This means that serodiscordant couples played out their lives in interpersonal spaces. As will be demonstrated in this section, serodiscordant couples made intersubjective interpretation of HIV and AIDS information.

Owing to their marriage relationship, serodiscordant couples experienced HIV and AIDS information as spouses. In the first place, all partners that were found HIV positive were encouraged to go for VCT with their spouses. HIV and AIDS information provided by VCT centres, ART clinics and hospitals was also of mutual importance to the two partners. However, evidence from interviews suggests that for some couples the two partners experienced HIV and AIDS information together while for other couples each partner experienced HIV and AIDS information individually. Some couples agreed to go for VCT together. HIV+ Male partner, couple #6 said *"I told her…we should go together for VCT, this will do us good and we will know our status. We went for testing at the hospital".* In other couples one partner went for VCT first. Since it is mandatory for all pregnant women to go for VCT, women were most likely to be the first to go for VCT. As explained by HIV+ Female partner, Couple #19 it was the responsibility of that partner to disclose the HIV test results to their spouse. *"That time I was found [HIV positive] while I was six months pregnant. After telling [my parents] I had to go and tell my husband who was away working in the gardens"*

Additionally, in some couples, only the HIV positive partners went to HIV and AIDS support group.

> *Researcher: Your wife is HIV positive; what HIV and AIDS information do you need*
> *Male partner (HIV-): I don't need any information, I just need encouragement...*
> *.*
> *.*
> *Researcher: You have said your wife goes alone to the support group, why?*
> *Male partner (HIV-): I work night shifts, sometimes day shifts. Like today I am on day shift, I just asked for time off (Couple #12)*

HIV infection in a serodiscordant marriage relationship was a source of suspicion and triggered feelings of betrayal. The HIV positive partner in couple #12 explained that she contemplated suicide because she did not know how her husband would react to her positive serostatus. She went for VCT when her husband was at work and when she was found positive she got

distressed. She said; *"at that time I was distressed a lot and thought about killing myself while my husband was at work so that he should find me gone. But being a religious person I changed my mind"*.

Some HIV negative partners asked their partners to explain the source of the HIV infection. In their explanation they believed that their spouses got infected through extra marital affairs.

> ***Researcher:*** *Can you describe what the experience was like to hear HIV and AIDS messages at that time.*
>
> ***Male partner (HIV+):*** *So many things were going on in mind when I was hearing the information at the time I was trying to get to terms with what happened with my wife. I was confused, I was deeply hurt. When I came back I was distress because I am negative and my friend is positive, 'what should I do?' I got to a point where I decided to chase her, I said; 'woman, pack up your things and go. Where did you get this thing? I look after myself well' (Couple #14)*

Similarly, an HIV negative partner in couple #18 contemplated divorce when her husband was diagnosed with HIV. The partner described how her siblings died of AIDS and fear she too would die if she stays married to her husband.

> *That time when I hear HIV and AIDS messages I was distressed, I thought about the children. He is positive, I am negative but in future I will be found positive, I was really distressed my brother…. 'What has happened here is disappointing and you, man, you will leave'. The reason is in my family I had many siblings but now only two of us are left. 'And you have given me this, who will look after my children, can I leave them with my father?' Look, just last year my sister died, living me with many orphaned children, what has happened is not good at all, my brother I am really distressed"* (HIV- Female partner, Couple #18).

For some serodiscordant couples the HIV negative partners assumed the responsibility of carers. However, this was distressing for some partners because they believed that HIV can be transmitted through a hand shake:

> *"Yes, they were just talking; saying that when someone is HIV positive we should avoid getting closer to them because they can transmit the virus to you. That distressed me because I eat from the same plate with my husband"* (HIV- Female partner, Couple #21).

or by mosquito bites:

"....sometimes they say on the radio that the virus can come from injections that are not sterilised, sometimes through blood transfusion, even mosquitoes…" (HIV- Male partner, Couple #13)

As carers of people living with HIV, the HIV negative partners needed information to assist them manage their relationship with their spouse.

"...then when I got counselling from the hospital which said you should not send him away. Continue with your sexual life, use condoms, secondly when he is ill, look after him. But when he has sores on his body and you want to bathe him, wear plastic bags in your hands. Never bathe him without plastic bags on your hands. Yeah, we were advised like that." (HIV- Female partner, Couple #21)

Serodiscordant couples in general, and specifically the HIV positive partners valued the company of other people living with HIV. The ART clinics and HIV and AIDS support groups provided opportunities for couples to interact and converse with others in a way that gave them hope. The conversational relationships with other people living with HIV, and people working in ART clinics and HIV and AIDS support groups assisted couples to go beyond the self. Couple #13 explained that:

"The difference is that at the hospital [ART clinic] we are a group and everyone is able to explain what they do to have a healthy life" (HIV+ Female partner, Couple #13).

In addition, other people living with HIV in the community were viewed as trusted sources of information. An HIV positive partner in couple #13 said "*I open up to people I know have a similar problem*". Similarly, HIV negative partners in couple # 22 and #14 consulted friends who were also in serodiscordant relationships:

"I heard that she was on ART, she was found [HIV] positive. Then I talked to her; I hear you were found with this disease? She said; 'Yes', you are on ART? She said; 'Yes, why are you asking me that question?' Then I said things are not okay at home, things are like this, this and this and I am distressed with these developments. She told me; 'Don't be distressed, that's very minor, just follow the advice you got from the hospital'. I said; 'really?' She explained everything and from that time all my worries were gone" (HIV- Female partner, Couple #22)

"... because I have a workmate who was found [HIV] positive. While we were talking he told me that; 'I am on ART and I just accepted it, even my wife', in his case the wife is negative. ... So I asked him in a disguised manner, I said; 'what happened?' and he told

me; 'my wife just accepted it, it happened and there was nothing to do about it'. From that time.....I just accepted" (HIV- Male partner, Couple #14).

All serodiscordant couples interviewed were religious and believed in the Almighty Other, God. In addition, because of the despondence and uncertainty which comes because of the hospital's inability to provide a cure for HIV, serodiscordant couples found solace in religious institutions. Religion assisted HIV positive partners to re-define their lives and find a sense of purpose in their lives. Couple #17 described how their pastor assisted them to re-define the meaning of their illness:

"Our Pastor supported us very much. I told him about the HIV status in our home. He told me that; aaah! God knows everything that happens to you, sometimes illnesses come because we are naughty, and sometimes they come by God's plan so that you do not stray away. I remember he told me that it is possible that if we didn't have this illness we might have departed from God's way. We would be saying everything is alright. But when there is something you always say 'Eeeeh let me stay in here, the greatest reward is waiting for me'" (HIV- Male partner, Couple #17).

In there they have a lived relation with the Almighty Other, God. When this relationship matures the holy books of one's religion becomes a source of comfort for people living with HIV. One HIV positive partner argued that the Holy Bible was more able to answer his questions than the 'world':

"Because, especially me, I like reading the Bible. And when I consider the Bible, when I compare the Bible with this world I come to the conclusion that this world doesn't have an answer but the Bible has and in heaven there is. This means that the world does not have a cure for AIDS but God has because he is the Creator" (HIV+ Male partner, Couple #11)

On the other hand, other relationships with religious institutions and leaders had bad influence on serodiscordant couples. Churches that claimed to cure HIV encouraged people living with HIV to stop taking ARVs after healing prayers.

"... because there was another gentleman within this neighbourhood; what was his name? He also died of AIDS, he could not go the hospital as he was discouraging people from going to the hospital, he used to pray a lot. When he prayed for people he used to tell them that they are healed and should not go to the hospital or take ARVs, many people died here, knowledgeable people dying, knowledgeable people, now his turn came , he failed to go to the hospital. People told him to go to the hospital but he run away to go to a hospital in Thyolo, he died on the way. I will just go to a hospital away from here, how can I go when I stopped people from going there" (HIV+ Female partner, Couple #17).

My data analysis as presented in this section suggests that lived others were important to the management of the HIV infection. The two partners experienced HIV and AIDS information together as spouses. Serodiscordant couples also appear to trust other people living with HIV as sources of HIV and AIDS information. In addition, others such as religious leaders instilled a sense of purpose for living for couples. However, results of this present study also suggest that there were other people who were a bad influence to serodiscordant couples.

5.5.1 God and ancestral spirits

As discussed in the preceding section, religion was accorded great importance in the lives of serodiscordant couples. However, other couples reported to have consulted traditional doctors who were believed to possess supernatural powers to determine the cause of illness. Traditional doctors were believed to be able to speak with ancestral spirits.

> *"When my relatives saw my illnesses they remembered another relative who faced similar illness. That time I was too ill to go with them so they just took my clothes to a traditional doctor. The traditional doctor told them those were spirits; they wanted to give me prophetic powers" (HIV+ Male partner, Couple #20)*

Although medically the illness was due to HIV infection, the traditional doctor claimed to have spoken to ancestral spirits. The invisible ancestral spirits told the traditional doctor that the illness was part of a process of giving out prophetic powers. Unlike assertions by *lived others* such as spouse and children there was no way of verifying what the ancestral spirits had said.

Unlike *lived others,* God and the ancestral spirits were not encountered as lived bodies. These are spirits and intangible. While lived others such as spouse, parent, children, pastor and peers were encountered in bodily form and through conversational relations; interactions with God and ancestral spirits were mediated by religious leaders and traditional doctors.

Evidence from interview conversations suggests that serodiscordant couples distinguished God from the practice of religion. As such couples had strong and shared belief in God, and varied and opinionated views about the intermediaries. Talking about pastors who claim that they can heal HIV and AIDS using prayer couple #17 said:

> *"it hurts our hearts because in the end for people to see the problem with that person they say God is the problem. They give people false home. … Let's leave God do his work as He sees it fit…. because they make God look like a failure while God never fails" (HIV-Male partner, Couple #17).*

Many people believed that God has the power to heal their HIV infection but they doubted the ability of the intermediaries to bring about that healing. Most couples, however, were able to distinguish between true and false intermediaries. Other couples believed they had a direct access to God through prayer.

> *"What is needed is faith, on your own it is possible to pray and you will be healed" (HIV+ Male partner, Couple #11)*

God was also able to remove anxiety that came as a result of a partner's diagnosis of HIV infection. Two HIV negative women in serodiscordant relationships interviewed claimed to have prayed and their anxieties taken away.

> *"...then when sleeping that night, I prayed then I saw the Lord entering my heart. All the anxiety was gone" (HIV- Female partner, Couple #21)*

In this excerpt, the woman claims that God or Jesus Christ entered her heart after which all her anxiety was gone. This interaction with the invisible God is different from that with *lived others* such as spouse and children. It is an act of faith and belief.

5.6   Chapter conclusion

The aim of this chapter has been to present the life world of serodiscordant couples as gleaned from the interview conversations. This contextualises the world in which the couples played out their lives. In addition, the chapter has identified God and ancestral spirits as a possible separate life-world existential.

Although these existentials have been identified and differentiated as distinct structures of the life world of serodiscordant couples, in reality they cannot be separated from each other. As stated by Van Manen (1997) the existentials form a complex unit that is the life world.

Serodiscordant couples referred themselves as being abnormal. They described how information coming from informal sources portrayed them as people whose "normal self" has been compromised by HIV and their lifespan truncated. Informal sources of HIV and AIDS information were the *lived others*. Therefore, the couples' conception of the *lived body* was tempered by views and prejudices of lived others. In turn, the conception of the lived body resulted into formation of future temporal dimension for both HIV negative and positive partners.

Serodiscordant couples described the different spaces they occupied as people living with, or affected by HIV. The primary space occupied by the couples is the home, which they described

as welcoming or neglectful. They also occupied other spaces such as ART and VCT centres, the hospital, the church, and community or village forums. These spaces were also inhabited by others, *lived others*. In these *lived spaces* serodiscordant couples' freedom for action was limited by *lived others* occupying the same spaces. For instance, in communities where serodiscordant couples lived, people protested when village chiefs wanted to give them coupons for buying subsidised farm inputs.

Chapter 6

Exploiting HIV and AIDS information

6.1   Introduction

The HIV pandemic is characterised by many medical and social problems such as the absence of cure, opportunistic infections, and stigma. Among the serodiscordant couples the problem was compounded by, among other things, the need to manage the marriage relationship and bear children. In addition, the need to manage the HIV infection gave rise to financial needs. Couples needed to buy medication and nutritious food. In order to meet these and other needs serodiscordant couples needed HIV and AIDS information.

In the preceding chapter I presented the life-world of serodiscordant couples using the four existentials: lived body, lived space, lived time, and lived others. I also presented a fifth existential of the life-world identified from my data. This chapter serves as a transition into chapter 7 where the experiencing of the phenomenon, HIV and AIDS information, is described. First, this current chapter will describe the needs serodiscordant couples had as they lived in their life world. In order to meet these needs the couples needed HIV and AIDS information. Therefore for each need, serodiscordant couples had corresponding information needs, which will be identified from interview conversations and discussed. Secondly, the sources of HIV and AIDS information that were used by the couples will be examined. The examination considers the preferences serodiscordant couples had for HIV and AIDS information sources.

6.2   Need for physical health

Joint United Nations Programme on HIV/AIDS (2013) asserts that when HIV infection is well treated and managed greater economic returns are realised as a result of increased employment and productivity. In addition, expenses associated with accessing medical services are averted. Serodiscordant couples that were interviewed associated good health with increased productivity in their gardens, where they grew crops to feed the family, and in small scale businesses. The results presented in this section focus on serodiscordant couples' need to maintain good physical health. In addition, the results suggest that couples sought biomedical and nutrition information in order to satisfy the need for good physical health.

Like any other person, partners in the serodiscordant couples interviewed wanted to maintain healthy bodies so that they could participate in economically viable activities to support

themselves, their families, and relatives. This desire to maintain healthy bodies was there before diagnosis of the HIV infection. Couples described physical decline and persistent illnesses that prompted them to go for VCT.

"I was getting ill frequently, and when I thought about it, I was going to the hospital may be four times in a month. Then I decided to go for testing. The same day I went for testing I was found positive. The same day I was counselled together with my wife and started ARVs". (HIV+ Male partner, Couple #18)

However, some serodiscordant couples had difficulties to identify the illness the HIV positive partner was suffering from before diagnosis of HIV.

"...it's like when he was found positive, at first he developed sores on his body. We went to Kamuzu Central Hospital for treatment, we went to Bottom Hospital for treatment, then people said try Mtengo wa nthenga, we went to Mtengo wa nthenga for treatment but it appeared all that medication was not working. Then he could not wear a shirt any more [because of the sores] and the illness went on and on. We could not understand what was happening, what illness is this? We did not know what was going on. When we went for VCT it was after suffering for a long time, we never knew anything, we never knew the cause". (HIV- Female partner, Couple #7)

During the interviews, most HIV negative partners did not talk about their health before diagnosis of HIV for their partners. However, the frequent mention of their partners' poor health suggests that they did not have major concerns about their own health.

After diagnosis serodiscordant couples believed healthy bodies were essential to successful management of the HIV infection. Some HIV positive partners were aware that a higher viral load was a sign of poor health and could be fatal. As such they wanted to make sure the viral load was kept under control. Abandoned by her husband, an HIV positive woman conceded that she was under pressure to satisfy her sexual drive by sleeping with other men. However, she was scared:

Female partner (HIV+): I am scared, if I have the virus it should be only that virus, not one should give me their virus to increase the number of viruses in my body. I am scared.

Researcher: Where does that fear come from, what causes it?

Female partner (HIV+): Fear comes from realisation that if I sleep with many men they will kill me; they will give me the viruses they have in their bodies, [the viruses] will enter my body and multiply and kill me (HIV+ Female partner, Couple #10 separated)

Although some couples did not directly describe the need for healthy bodies, this was clearly evident in the talk about their achievements. For instance, some couples said they had managed to grow sufficient food for their families because of good health. One of the best descriptions was provided by couple #11:

"I don't have major problems; I can say that the only time I was very ill is that time 2007...I work in the garden very well without any problem" (HIV+ Male partner, Couple #11)

Similarly, in the following excerpt, an HIV positive partner talks about the significance of a healthy body:

"I am very happy; my health is good. I am able to work; I have four and a half plots of maize crop and it is this high (shows the height with a hand). Weeding, in fact [the support group manager] stopped us weeding the maize gardens to come and meet you" (HIV+ Female partner, Couple #19)

Further, most serodiscordant couples needed good nutrition that could make their bodies healthy and strong. "*Sometimes money is not available then food is also problematic*" (HIV- Female partner, Couple #7). One couple attributed the severity of ART side effects to lack of good nutrition. HIV negative male partner in couple #14 said:

"But the problem is nutritious food for her because the problem is that her medication requires good nutrition. We are trying but it is not enough" (HIV- Male partner, Couple #14)

As a result of their desire for good health serodiscordant couples needed information about the illness they were suffering from and its prognosis. Before the diagnosis of the HIV infection the HIV positive partner was suffering from many diseases that were difficult to treat. This triggered information needs in order to explain the cause of these illnesses.

"That time I did not know anything; I was very ill, coughing frequently, general body pain, malaria. Then my husband said; 'you have been sickly for some time, let's go to the hospital to find out what is wrong with you, we should get tested'" (HIV+ Female partner, Couple #8)

In some couples, the first to be tested was the HIV negative partner. Since most HIV and AIDS information states that HIV is largely transmitted through unprotected sex, they both believed if one of them is negative then both are. Having established their HIV statuses based on test results of one partner, couple #17 described how they struggled to make sense of illnesses of the female partner:

"The state we are in, for us to get much information, we got it from... you know, there used to be a newsletter, [asks his wife] what was the name of that newsletter? That NAC[2] newsletter? In those newsletters they used to describe the signs, this and that, low immunity, HIV and AIDS, and those newsletters were good... whenever I told her to go for testing she always said; why should I waste time when you as a blood donor are tested all the time, can you see that....Then in the same newsletters I read about a couple from Mzimba who had been married for 20 years, yes, the wife was negative but the husband was positive. Then when I saw that I said to her; can you see this! This could be possible with us" (HIV- Male partner, Couple #17)

After the diagnosis, most couples were confused about their different HIV statuses. They wanted to know the reasons for their different HIV statuses. According to the couples interviewed personnel in hospitals, VCT and ART centres did not explain clearly the cause of serodiscordance:

"I don't understand, because when I ask this one, they will give you a different answer, the other will give you yet a different answer, another a different answer; now what is the exact thing about serodiscordance" (HIV+ Male partner, Couple #1)

After HIV testing most HIV negative partners did not believe the results. In some cases, evidence shows that couples were not given the opportunity to ask question about their HIV status. One couple said:

"They just tell me you are negative" (HIV+ Male partner, Couple #1)

The two partners in a serodiscordant couple appear to have different but overlapping information needs. The HIV positive partner needed information about the development of HIV in their bodies. With the risk of opportunistic infections, HIV positive partners were mostly on the alert to prevent attacks.

"I already had cervical cancer screening. I don't feel ashamed to go for screening of any opportunistic infection on my body. I want to know. When I note a slightest problem I rush to the hospital where they explain to me" (HIV+ Female partner, Couple #10 separated).

On their part, most HIV negative partners needed information about their HIV status and how to protect themselves from infection.

---

[2] Malawi National AIDS Commission

"When he was found with the virus I wanted to understand. The way we had sex was frightening me, I was frightened, and how will I continue having sex with him" (HIV- Female partner, Couple #21)

Most HIV negative partners reported going for regular VCT in order to have information about their HIV status. However, most HIV negative partners did not believe their HIV test results. As a result, they needed a clear explanation of the reasons why they had different HIV statuses when they had unprotected sexual contact.

"My question is; my husband was found [HIV] positive and we always had unprotected sex but when I go for [HIV] testing, I am always found negative, why is that the case?" (HIV- Female partner, Couple #1)

After diagnosis of the HIV infection all serodiscordant couples interviewed anticipated the physical decline of the HIV positive partner. At the ART clinics and HIV and AIDS support groups couples were advised to ensure that they were eating a balanced diet in order to cope with the side effects of ARVs and have a healthy life. All serodiscordant couples interviewed mentioned that good nutrition was significant for the well-being of a person living with HIV.

"The other information I received was that...we should eat a wide variety, vegetables like sweet potato leaves, eating a wide variety, that's relish" (HIV+ Female partner, Couple #2)

Similarly, couple #6 described the essential requirements for maintaining a healthy body for people living with HIV:

"The main points are: 1. Eating a balanced diet, sleeping on a comfortable bed, looking after one's body, regular exercise, eating a wide variety of food, these things are essential for us who are HIV positive" (HIV+ Male partner, Couple #6 on separation).

Although couples demonstrated awareness of the basic nutrition facts, they expressed the need for a guide that provided examples of locally available foods that would make up a nutritious meal for a person living with HIV. Many serodiscordant coupes wished they had some information objects on nutrition in their homes. As stated by the HIV positive partners in couple #3:

There is a chart which specifies the six groups of food, I can't remember who produces those, it is only found in hospitals only so if I don't go there am not able to read it. (HIV+ Female partner, Couple #3)

In some cases, couples who had access to nutrition information, with examples of foods that make up a nutritious meal, were not able to identify locally available equivalents of the foods given as examples. They had questions such as:

"For example, on the radio they just say a person living with HIV needs to eat six groups of food. But what foods make up the six groups, you see, it's is not known" (HIV- Male partner, Couple #14).

All serodiscordant couples interviewed demonstrated awareness of the effect of HIV infection on the immune system. However, only two couples talked about CD4 count as a measure of the immunity levels and an indication of vulnerability of their bodies to opportunistic infections. The first couple said that CD4 count and not physical appearance is the best indicator of the development of the HIV disease.

"When you go to the health centres you are told that; 'we can't give you [nutritional flour] because you look healthy', they don't know that it's the CD4 count that explains the health status of one's body" (HIV+ Female Partner, Couple #3)

"...they tell you to stand on a weighing scale, and falling all over yet they know the problem with this illness is that when immunity has gone down one can collapse anytime and die" (HIV+ Female partner, Couple #3).

Results presented in this section suggest that HIV is first experienced through the physical decline of the lived body. Therefore serodiscordant couples needed information such as on nutrition to maintain good physical health. The next section presents results on biomedical needs which are intertwined with physical health needs.

6.3   Biomedical needs

The HIV positive partners experienced major physical changes in their bodies before and after diagnosis. These changes necessitated medical interventions. As presented in section 6.2 serodiscordant couples needed good physical health in order to be productive in the home and the community. However, the physical health of the HIV positive partners was compromised by opportunistic infections that were exacerbated by low immunity arising from HIV infection. Results presented in this section are on needs to understand the nature of HIV and the treatment plans available.

Prior to the diagnosis of HIV infection most HIV positive partners faced different kinds of illnesses that were untreatable. Some of the illnesses mentioned during interviews were shingles (Couple

#22), malaria (couple #24), diarrhoea (couple #14, #24), headaches (couple #14), sores on the body (couple #7), tuberculosis (couple #17), and some unidentified illnesses (couple #13). Other couples went for VCT when the female partner was pregnant and they wanted to know her HIV status so that they could save the unborn baby from HIV infection.

HIV positive partners experienced different changes in their bodies. Before being diagnosed as HIV positive, HIV positive partners suffered various illnesses that were mistaken for normal diseases. To the surprise of the couples these illnesses did not go away until the HIV infection was diagnosed.

> *"I suffered from shingles. When I suffered from shingles I went to the hospital and when they gave me medication I got better. But after a few months my body was itchy, I was scratching all the time, all over here. All the body was itchy" (HIV+ Male partner, Couple #22)*

After diagnosis they suffered from illnesses that were not expected as they were on ART. The HIV positive partner in couple #3 was convinced by ART counsellor that if she follows the advice given she would live a normal life. However, she said:

> *"I was surprised that I was having various illnesses such as swelling of the genital area, sores would come out and vaginal fluid coming out continuously" (HIV+ Female partner, Couple #3)*

On the other hand, because of compromised immunity there were some illnesses serodiscordant couples expected.

> *"Women with HIV like me are at risk of developing [cervical] cancer, yes, [cervical] cancer can develop quickly because we have HIV" (HIV+ Female partner, Couple #10 separated)*

After diagnosis of the HIV infection in their spouses, HIV negative partners were anxious of any illnesses they suffered. As discussed in sections 5.2 and 5.4 HIV negative partners believed the virus was hiding in their body and any illness was thought of as the manifestation of the HIV infection. HIV negative female partner in couple #22 said:

> *"I go to the hospital, when I feel any pain, when I feel unwell, I go for testing" (HIV- Female partner, Couple #22)*

Other HIV negative partners did not wait for illnesses to go for HIV testing. Every opportunity for HIV testing that availed itself was used to check their HIV status. Female HIV negative partner in couple #11 probably provides a good description:

> "And when I hear there is blood testing, I rush to get checked. May be that time the machine missed [the virus] or maybe something has happened. But I am found, in many places, I am found in many places because of encouragement from my husband" (HIV-Female partner, Couple #11)

As the HIV pandemic unfolded new ART regimens were introduced in order to improve the effectiveness of managing the illness. However, serodiscordant couples viewed the changes as a source of worry as new regimens came with new side effects.

> "During the past time when I take ARVs my legs were hurting, when I explained to people at the hospital they gave me different ARVs…..when I take the new ARVs am fine but sometimes you find the head is hurting on one side, sometimes the whole head, sometimes I am just weak. So I ask myself 'could it be because of poor nutrition?'" (Couple #14)

As a result of the physical decline of HIV positive partners described in this section serodiscordant couples started looking for information. Couples' biomedical information needs were related to their desire to know more about HIV and AIDS, and the associated opportunistic infections.

First couples wanted to know how to live with the HIV virus. Some couples needed basic information about the implications of the HIV infections on the body. One HIV positive partner claimed that when he asked for this information from some HIV and AIDS information sources and "*many of them just say it is a plague*" (HIV+ Female partner, Couple #12).

Although world over all experts agree that there is no cure for HIV, most serodiscordant couples believed that cure was available. In addition, some couples claimed they knew other people who were cured. While other claims of a cure for HIV were dismissed as untrue, some were believed.

> "We heard somewhere people saying that medicine that can kill the HIV virus is available only that the organisations or government just don't want to give people the medicine. We always try to find out what is stopping them from giving out the medication" (HIV- Male partner, Couple #13)

Similarly, another couple heard about a cure for HIV on the radio and they were excited.

"Today I was listening to MBC Radio 1, they were saying that they have found Garani MW1...people were testifying, testifying that they were cured and this excited me. I wish I could fly and get that drug" (HIV+ Male partner, Couple #16)

Evidence from couples' stories suggests that serodiscordant couples were more likely to believe HIV cure that was tangible than claims that were intangible such as prayers. All couples, regardless of the strength of their religious faith, never believed pastors and prophets who claimed to heal people living with HIV using prayer.

Although National Statistical Office (NSO) and ICF Macro (2011) states that HIV and AIDS knowledge in Malawi is universal, some serodiscordant couples appeared to lack some basic information about HIV and AIDS. This was evidenced by some information some couples believed were correct but I thought were mythical. During the interviews couples expressed the need for more information about HIV and AIDS.

Evidence from interviews and observations suggests that serodiscordant couples did not actively seek biomedical information. Although couples expressed the need to know more about HIV and AIDS, and serodiscordance they did not actively seek that information. Information sought by couples that could be classed as biomedical was information about their illness, HIV status, progression of HIV and the serodiscordance.

6.4   Need to explain serodiscordance and prognosis of HIV

This section presents results on the need to manage the difference in HIV statuses between the two partners in serodiscordant couples. Most couples chose to stay together and they needed to make HIV positivity co-exist with HIV negativity. In addition, they feared that death was eminent and they needed to slow down the transition of HIV infection into AIDS, and prevent transmission of the virus to the HIV negative partner.

As discussed in section 6.2 serodiscordant couples appeared to be confused about their HIV statuses. For most couples the HIV infection came as a surprise which made them to have various questions. The first question concerned the source of the HIV infection in the home. The level of questioning and suspicion increased after the other partner was found to be HIV negative.

"That time I was distressed since one was found positive and the other HIV negative and you know the human heart is troubling, yeah. That time our marriage was shaken I just wanted us to divorce" (HIV- Female partner, Couple #18)

Most serodiscordant couples I interviewed expressed dissatisfaction with explanations for the causes of serodiscordance they got from VCT counsellors. Serodiscordance was viewed as being contradictory to HIV and AIDS information which stated that HIV is transmitted, among other means, through unprotected sex. Couples interviewed were confused because they were in marriage relationships where they engaged in unprotected sex yet one partner remained HIV negative.

> *"My life was troubled when I was found negative. I was confused we always had unprotected sex and they say I don't have the virus? And I was told that I was pregnant; will I surely give birth to a healthy baby? (HIV- Female partner, Couple #11)*

The sentiments were also expressed by HIV negative partner in couple #1.

> *"They always tell me I don't have [the virus], and I always tell them my husband is like this. I don't understand how it happened, one has [the virus] and the other doesn't, yet we have always had unprotected sexual contact" (HIV- Female partner, Couple #1)*

Based on what they claimed to have heard, some HIV positive partners expected to be healed. Some couples claimed to have heard that other people had their HIV infection cured. As discussed in section 6.3 some couples believed that a cure for HIV was available and that government or some organisations were withholding it. They *"want to find help, medicine that can cure [them]" (HIV+ Female partner, Couple #13)*

For this reason, serodiscordant couples needed HIV and AIDS information that could clearly explain the reasons for their different HIV statuses. Further, serodiscordant couples were anxious about the prognosis of their serodiscordance. The anxiety resulted from the conflicting information that is provided by VCT centres and HIV and AIDS support groups.

During the interviews some HIV negative partners described their fears about the future. As such they stated that they needed information that would assist them map out the different possible scenarios of their future lives. In addition, both partners said they needed information to constantly conduct risk assessments and assess the possibilities of them infecting each other.

6.5   Need for emotional and social support

Serodiscordant couples' narratives provide evidence that they experienced emotional stress after discovering their HIV statuses. In this section I present results that indicate that the couples needed to be supported emotionally in order to live positively with HIV in their societies. When I went to some HIV and AIDS support groups in Lilongwe to recruit participants it was reported that

most serodiscordant couples had separated. This was an indication that most couples were not able to manage the emotional stress that came with serodiscordance. An HIV positive male partner whose wife left explained how he had to seek the intervention of the police for his wife to come out of hiding and discuss the status of their marriage:

> *"Then I went to police to file a complaint at the Victim Support Unit. They gave me a letter to take to our marriage counsellors; that's when my wife came out of hiding. When she came out we talked about what had happened and she said she doesn't want me because I am HIV positive" (HIV+ Male partner, Couple #6 separated)*

Partners who were on separation from their spouses felt their rights were violated. Further, they viewed the actions of their spouses as breaking their marriage vows.

> *"...what happened in this house is harassment, because if you share vows with someone that we will not part until death even if you fall ill and they decide to leave you, in my opinion that's harassment. Besides, that's adding on to your illness when they should have looked after you" (HIV+ Male partner, Couple #6 separated)*

Some HIV positive partners interviewed described the accusations that came from their partners where it was intimated that the positive HIV status was because they were promiscuous. During the interview with couple #4 the male HIV negative partner emphatically said in the presence of his wife that it is only through promiscuity that one can get infected with the HIV virus.

> *"When I heard these [HIV and AIDS] messages I knew there is a problem, I knew that there is no need to be careless because this disease has no cure. And two, adultery is bad, because most people are getting infected with this disease because of adultery" (HIV- Male partner, Couple #4)*

And the female HIV positive partner responded:

> *"This issue bothers me a lot, I have never been adulterous. In fact I always fight with my husband; 'where did you get this disease, it means you are promiscuous' I always tell him, no, dad I got this disease from the birth control injections..." (HIV- Male partner, Couple #4)*

Similarly, the HIV positive partner in couple #14 complained of verbal harassment by her husband. She said that during arguments the husband says "*maybe because you are on ARVs that's why you are always out of your mind and always refuse sex" (HIV+ Female partner, Couple #14)*. On his part, the husband confessed to harassing his wife. He said sometimes he would refuse to eat food prepared by his wife and when the wife tried to discuss the problem was, he

would respond; "*go where you got this [virus] because if it were me who brought it then I would have also been positive*" *(HIV- Male partner, Couple #14)*.

HIV positive partners explained that they needed information that would provide emotional support when faced with accusations of being promiscuous. On the other hand, HIV negative partners that were committed to staying together with their HIV positive spouses needed HIV and AIDS information that would allay their fears about serodiscordance. This need was noted by the HIV positive partner in couple #13 when she said:

> "*For me I take it as my responsibility, because my friend is okay and it's me who has the problem, I am supposed to bring him HIV and AIDS information so that he should be encouraged*" *(HIV+ Female partner, Couple #13)*

Although their HIV statuses were negative, HIV negative partners also experienced emotional distress. First HIV negative partners anticipated death of their partners. Where the HIV positive partner was the breadwinner, the HIV negative partner also worried about the welfare of the children after death of their partner.

> *That time when I hear HIV and AIDS messages I was distressed, I thought about the children. He is positive, I am negative but in future I will be found positive, I was really distressed my brother. (HIV- Female partner, couple #18)*

On the other hand the HIV positive partner in couple #3 said she needed HIV and AIDS information that would encourage her amidst threatening messages:

> "*On my part I need messages that can encourage me because the problem is that some messages are threatening. So I need messages that should give me hope; okay I have a problem but with that problem is there any hope?*" *(HIV+ Female partner, Couple #3)*

This interview excerpt alludes to HIV and AIDS information that is not needed. This is information that is threatening and brings no hope. As presented in this section, some of this information can come from spouses.

Mostly social support for people living with HIV was provided by HIV and AIDS support groups. However, most HIV and AIDS support groups were established by people living with HIV without any external support. In some cases support groups were given financial support, skills training and information materials. However, serodiscordant couples in HIV and AIDS support groups in the rural areas reported need for training in support group leadership.

"On the other hand I desire to have leadership skills. With leadership skills I can reach out to many people and teach them about HIV and AIDS. I do teach people but using the little knowledge I have. But with training I can reach out to more people and teach them better" (HIV+ Male partner, Couple #21)

The interviewee in this excerpt refers to training that would equip him with general knowledge about HIV and AIDS, in addition to leadership skills. Although some couples were involved in HIV and AIDS information campaigns, they had not been trained. In addition, most couples lacked information literacy skills. This was evidenced by their responses to the question: Are there HIV and AIDS information you think are false/not valuable? Most serodiscordant couples answered that all HIV and AIDS information were valuable and true. Both partners in couple #8 agreed that:

"There is no HIV and AIDS message we are not happy with, all information is important because it's for our knowledge" (HIV- Male partner, Couple #8)

Due to the lack of information literacy skills, most couples believed some HIV and AIDS information that could be considered to be mythical. Besides, some interviewees confessed to having problems answering questions asked by people they reached out to during HIV and AIDS information campaigns.

6.6 Desire to bear children

Most of the serodiscordant couples interviewed in this study were of reproductive age. Of the 45 participants in serodiscordant relationships interviewed, only13 participants were in the age group of 45-64; and 3 were over 65 years old. The medical requirement to consistently use condoms was viewed as barrier to bearing children. Results presented in this section are on the desire to bear children while preventing the transmission of the virus to the HIV negative partner, and the baby.

Serodiscordant couples, like any other married couple, were socially expected to bear children. A male HIV positive partner, who was abandoned by his wife, reported that he was aware of relatives' expectations for the couple to bear children.

"...on that issue, relatives expected, as married couple, to continue the family lineage, to have children. They expect marriage to bring out fruits" (HIV+ Male partner, Couple #6 separated)

In addition, evidence from interview conversations suggests that male partners were eager to demonstrate their masculinity by making their wives pregnant. This sentiment is well captured in

what a male HIV negative partner said about his understanding about masculinity. The wife said that "*now it's my husband who pesters me that he wants another baby*" (HIV+ Female partner, Couple #19). When I asked the husband to explain why, knowing there was a chance of getting infected, he wanted to have unprotected sex with his wife in order to have a baby, he said:

> "*...when you know that this is your wife you should teach her that I am the man and she is a woman……. I should ejaculate before she reaches orgasm then she will get pregnant and I will not be infected; because I have gone first. Do you understand that? So a woman is free to get pregnant and I cannot get infected*" (HIV- Male partner, Couple #19).

For some couples the desire to bear children was shared between the two partners:

> **Researcher:** *Do you expect to have another child?*

> **HIV+ Male partner:** *In this case we don't because this one was born while I was on ART. I discussed with my wife that what should we do based on what they are saying. We went to the hospital for another counselling session for us to have this baby (Couple #20).*

for others it was only one partner desiring to have children.

> "*Sometimes my husband tells me; 'my wife, I want us to have a baby'. But when I go to the support group we are taught different things, they tell us that people that are HIV positive should not bear children. Sometimes I am encouraged when I hear on the radio; they say that HIV positive people can bear children with guidance from the hospital*" (HIV+ Female partner, Couple #12)

Relatives' expectations for children also influenced serodiscordant couples to have children. An HIV positive partner who at the time of the interview had separated from his spouse explained how expectations for a baby from his relatives influenced his desire to have one:

> "*The woman I married had a child from her previous marriage when I didn't have any. This was a problem because I married her and she had this baby, and even her relatives expected me to bear a child with her. 'What do I do with this problem?' This problem troubled me*" (HIV+ Male partner, Couple #6)

Although couples that decided to bear children did so after consulting counsellors in ART or VCT centres, this was a distressing decision for HIV negative and positive female partners. Some HIV negative partners were worried that they would be infected. On the other hand, although their partner was HIV negative, some HIV positive partners were concerned that unprotected sex would increase their viral load. One HIV negative partner remarked: "*the nature of questions I*

had, I was asking myself; if we do things like these, are we not going to infect each other?" (HIV-Female partner, Couple #20). Similarly, the HIV positive partner in couple #14 was hurt because her husband was refusing to use condoms.

> *"In my heart I was hurting because of what we were advised at the hospital that we should use condoms so that the viruses should not multiply in your body, the viruses should be few" (HIV+ Female partner, Couple #14).*

HIV and AIDS information was also experienced as a parenting tool. Some couples had lost children and grandchildren to AIDS. For example Couple #9 lost their "*daughter-in-law because of this disease…and first born son…and second born daughter because of AIDS*" and couple #4 had lost "*three children plus a son-in-law*". In addition, other couples had children living with HIV. HIV positive partner in Couple #10 (separated) said, "*I am looking after a small boy who is also HIV positive*" and couple #13 said that "*our child was also found HIV positive*". Because of these encounters with HIV and AIDS, most serodiscordant couples used HIV and AIDS information to bring up their children. Couple #20 told me that:

> *"And we use the counselling we receive so that we are able to do things that will ensure that children we have should not get infected with the virus" (HIV+ Male partner, Couple #20)*

Evidence from interview conversations suggests that desire for children described in this section triggered information needs relating to reproductive health of people living with HIV. In the examples given the couples got information from the hospital and HIV and AIDS support groups. However, other couples got information from the radio and friends.

> *"Yes, we hear on the radio that a person living with HIV can have a baby that has no virus as long as you follow advice from the hospital" (HIV- Female partner, Couple #18).*

In most couples both partners expressed their need for reproductive health information. These couples wanted to know health risks associated with getting pregnant and bearing a child. Specifically, HIV negative partners were worried about the risk of being infected and therefore expressed the need for information on how they can protect themselves. On the other hand, female HIV positive partners expressed the need for information on how their pregnancy could affect their immunity. They were also worried about transmitting the virus to their spouses. In some serodiscordant couples both partners talked about the need for information on how they could protect their unborn baby from being infected with HIV.

"My life was troubled when I was found negative...and I was told that I was pregnant, will I surely give birth to a healthy baby? ..... I started walking from hospital to hospital to save my baby, until I finished off at Baylor College Children's Hospital where they certified my baby non-reactive" (HIV- Female partner, Couple #11).

As discussed in the previous section, serodiscordant couples wanted to maintain healthy bodies. For some couples bearing children was viewed as a threat to that goal. Some couples mentioned CD4 count when explaining the process they were advised to follow when they decide to bear children.

"There is a CD4 count machine at Lobi and we are told to first have our CD4 count checked. If your immune levels are high you can have a baby but they should not exceed three, because our immunity is compromised" (HIV+ Male partner, Couple #21).

Results presented in this section suggest that the desire to bear children had two dimensions. The first concerns the biological process of becoming pregnant, and giving birth with respect to the risks of HIV transmission. The second dimension is where serodiscordant couples were planning for the future. They appeared to be considering a possibility of raising HIV positive children, and their longevity to look after the children. These needs caused serodiscordant couples to need HIV and AIDS information.

6.7   Financial needs

HIV and AIDS came with new financial demands on the family. During the interviews most serodiscordant couples conceded that they were struggling financially. Couples faced financial burden due to loss of income where the HIV positive partner was the breadwinner. On the other hand, even where the HIV positive partner was not the breadwinner, couples faced financial burdens as they had to pay illness related costs.

As noted in Chapter 4 most partners in serodiscordant couples were engaged in work that required physical fitness such as farming, bricklaying and carpentry. For the other couples, they were either running small scale businesses or contemplating starting one. Couple #22's financial needs were related to managing the HIV infection by ensuring the HIV positive partner and the rest of the family had good nutrition.

"I wish we had access to business loans so that we could start small businesses. Then we will be able to buy what we need, food to improve the health of our bodies" (HIV+ Male partner, Couple #22)

Similarly, many other couples needed business loans to either start small businesses or boost existing ones. Sadly, couples that tried to access bank loans reported that they were rejected as they were considered high risk borrowers. According to the HIV positive partner in couple #1, people infected with HIV were considered to be dying and banks appeared not to want to risk by lending money to them. He said:

> "...even when you want to get a bank loan; they say, 'if we give him even MKW5,000,000.00 [approximately £7,500], he says he want to do business, will he repay? Won't he die?'" (HIV+ Male partner, Couple #1)

In case of loan or grant schemes targeted at people living with HIV, serodiscordant couples felt these were abused by managers responsible for disbursing the loans. Couples claimed that money that was meant to benefit people living with HIV was diverted to non HIV related activities. The HIV positive partner in couple #11 told me about his participation in the writing of a funding proposal. "*When the money was received it was diverted to buying maize and they said; 'we will open a boarding school'*". This discouraged him and he stopped participating in the activities of that HIV and AIDS support group.

In order to address the need for business loans serodiscordant couples needed information about organisations that offered such loans. Couples needed information about organisations that provided loans, procedures for applying for business loans, and organisations that provided items to be used in starting small scale businesses. Serodiscordant couples also thought managers of banks, loan schemes and other government departments were ill informed about HIV and AIDS. As a remedy, couples proposed that correct information about HIV and AIDS should be provided to this group of people. Remarks by the HIV positive partner in couple #1 is indicative of this proposal:

> "*Messages like these should also be made available to even government officers. They let them know that these people's lives are not finished, they can live a long life and they can do anything everyone else can do*" (HIV+ Male partner, Couple #1).

This section has outlined some financial challenges that were faced by serodiscordant couples. Remarks made by the couples suggest that there were some implicit restrictions that prevented people living with HIV from obtaining loans. In addition, results presented in this section have shown possible links between physical health and financial needs. In order to address these financial needs couples needed access to HIV and AIDS information.

6.8   Information sources used by serodiscordant couples

Sections 6.2 to 6.7 have established the needs of serodiscordant couples and the associated information needs. During the interviews couples mentioned different sources they used to access HIV and AIDS information. I will classify information used by serodiscordant couples as either formal or informal and personal or impersonal.

According to Kaye (1995, p. 13), "formal sources may be defined as those which are constituted in some regularized or legal manner in relation to the user, whereas informal sources have no such basis". Thus for serodiscordant couples in my study, formal sources of HIV and AIDS information were those that were established with the mandate of Malawi Government through National AIDS Commission. On the other hand, informal sources were those that were casual, such as everyday talk. Personal sources of information are those that communicate personally or directly to the individual and impersonal sources communicate to broad audiences through mass communication activities (Aguilar, 1967; Auster and Choo, 1993). Based on the criteria and definitions outlined here **personal-formal** sources are those that had the mandate of or regulated by the Malawi Ministry of Health to provide information to people, and the information was provided on one-on-one basis. Examples were information provided to one or both partners in a clinic or hospital consultation, and information provided through home visits or in a clinic by research clinicians or nurses. **Personal-informal** sources were those that did not have the official mandate but were accessed through one-on-one everyday social interactions. **Impersonal-formal** sources are those that had the mandate of or regulated by the Malawi Ministry of Health and targeted broad audiences. The results of my study suggest that radio and television was used by the Ministry of Health to broadcast HIV and AIDS programmes therefore I categorised these under **impersonal-formal** sources. However, evidence from interview conversations also suggests that radio and television presenters' commentaries on HIV and AIDS issues, which were often based on their opinions, were considered HIV and AIDS information. Therefore, radio and television were also categorised as **impersonal-informal** sources of HIV and AIDS information. Table 6.1 summarises information sources used by serodiscordant couples in four quadrants.

Formal	Informal
A Doctors Nurses HIV and AIDS counsellors HIV and AIDS research projects HIV and AIDS management centres VCT centre counsellors	**B** Spouse • Word of mouth • Body Peers • Word of mouth • Body Marriage mediators HIV and AIDS support groups
C Newsletter Books Charts Leaflets Children's school textbooks Radio Television	**D** Music Church Television Radio Area development committees Village development committees Political rallies HIV and AIDS support groups Workplace support groups Antenatal clinics

Personal (rows A, B) / Impersonal (rows C, D)

Table 6.1: Information sources used by serodiscordant couples

Quadrant A: Personal – formal

Serodiscordant couples reported receiving formal HIV and AIDS information from personal sources such as doctors, nurses, VCT counsellors and ART counsellors. During the interviews couples did not mention VCT and ART counsellors. Professionally, these are nurses or clinicians and in some cases doctors. Therefore, they were referred to as doctors or nurses. Because of this lack of differentiation it was difficult to assess serodiscordant couples' preferences of personal-formal sources of HIV and AIDS information. However, one couple's description of a visit to the out-patients department of a major hospital in Malawi provides evidence that suggests

that couples would feel more comfortable with personal-formal sources that were themselves living with HIV or working in ART or VCT clinic. Couple #3 said:

> "When I went to the hospital, that day we were treated by a doctor who was not living with HIV (a sigh of disappointment) then the doctor came out into the waiting room and he said; 'All women with children here, you will die, the President is failing to buy medicine, for this reason you will all die' so for me I received this information because it was coming from a doctor, if government appointed him to be a doctor then they knew he can tell me useful information" (HIV+ Female partner, Couple #3)

Another HIV positive female partner remarked:

> "Someone who does not have the problem I find it difficult to open up to them and discuss these issues. I open up only to those I know have this problem; these are the ones I open up to" (HIV+ Female partner, Couple #13)

Personal-formal sources were largely available in hospitals, ART and VCT centres. In some cases HIV and AIDS talks were made in HIV and AIDS support groups. Only in rare cases did personnel from hospitals, ART and VCT centres visit serodiscordant couples in their homes.

> "In the past, a doctor from [Kamuzu] Central [Hospital] used to visit us a lot, but now he stopped. He doesn't come anymore" (HIV- Male partner, Couple #4)

Quadrant B: Personal – informal

Personal-informal sources of HIV and AIDS information appeared to have the biggest influence on the lives of serodiscordant couples. While personal-formal sources were either solicited or accessed at designated times, personal-informal sources were part of the everyday commentary on social issues. In addition, personal-formal sources were good at perpetuating myths about HIV and AIDS. One would expect that HIV positive partners who had access to many sources of HIV and AIDS information would be knowledgeable enough to dismiss myths. However, the HIV positive in couple #12 for instance was bothered by information provided by some personal-informal sources:

> "What I want to know, some people say that people who have the virus that is the end of their lives, so I want to know, is that true or not?" (HIV+ Female partner, Couple #12)

Evidence from interview conversations suggests that serodiscordant couples believed that HIV can be transmitted by mosquitoes. Other HIV negative partners also believed that they could be

infected with HIV by shaking their HIV positive partner's hand. As presented in the following interview excerpt, HIV negative partner in couple #21 got the mythical information from peers. She said:

"Yes, they were just talking; saying that when someone is HIV positive we should avoid getting closer to them because they can transmit the virus to you. That distressed me because I eat from the same plate with my husband" (HIV- Female partner, couple # 21).

Other personal-informal sources of HIV and AIDS information had a positive influence on serodiscordant couples. Two HIV negative partners reported having used personal-informal sources for HIV and AIDS information on serodiscordance. The first HIV negative partner said:

"I heard that she was on ART, she was found [HIV] positive. Then I talked to her; I hear you were found with this disease? She said; 'Yes', you are on ART? She said; 'Yes, why are you asking me these questions?' Then I said things are not okay at home, things are like this, this and this and I am distressed with these developments. She told me; 'Don't be distressed, that's very minor, just follow the advice you got from the hospital'. I said; 'really?' She explained everything and from that time all my worries were gone" (HIV- Female partner, Couple #22)

The second HIV negative partner consulted a friend who was positive and in a serodiscordant relationship.

"... because I have a workmate who was found [HIV] positive. While we were talking he told me that; 'I am on ART and I just accepted it, even my wife', in his case the wife is negative. ... So I asked him in a disguised manner, I said; 'what happened?' and he told me; 'my wife just accepted it, it happened and there was nothing to do about it'. From that time.....I just accepted" (HIV- Male partner, Couple #14).

As presented in Table 6.1, the body was an important source of HIV and AIDS information for serodiscordant couples. As quoted in sections 5.2 and 5.5 some HIV negative partners were advised by health workers to look out for signs of risk of HIV transmission on their partner's body, and wear plastic bags in order to protect themselves.

Further, some HIV and AIDS information serodiscordant couples had in their homes described what an HIV infected person's body looks like. Some information objects had graphic images of people living with HIV. As shown in Figure 6.1 couples were able to see signs on their or partner's body and relate to the signs of HIV infection.
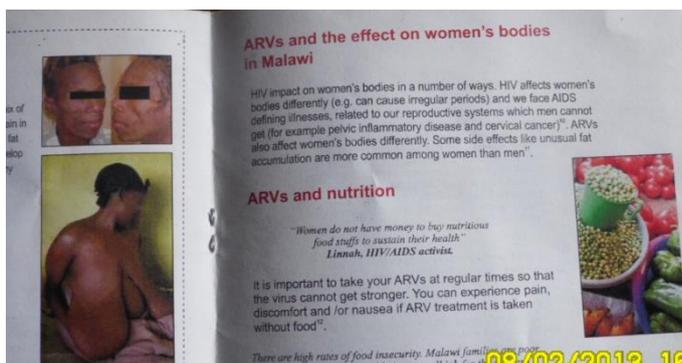
Figure 6.1: HIV and AIDS information describing the body of an HIV infected person

Serodiscordant couples also received HIV and AIDS information through communicative actions of other people. The male HIV positive partner in couple #6, for example, felt discriminated when he saw people refusing to assist an HIV person injured in an accident for fear of being infected.

Quadrant C: Impersonal – formal

Impersonal-formal HIV and AIDS information sources had the potential to be most important sources of information for serodiscordant couples. Most couples were finding that impersonal-formal HIV and AIDS information sources relevant to serodiscordance were rare. Some books couples said were useful were said to be found in hospitals and HIV and AIDS management centres only.

> *"…but because this book is only found at NAPHAM and it is difficult to have it" (HIV+ Female partner, Couple #3)*

However, the conversation with couple #3 suggests that access to impersonal-formal HIV and AIDS information is partly limited by the associated costs. The HIV+ Female partner, Couple #3 said:

> *"Now for me to get where the book is available, read and come back; for us that is a lot of money. I would be happy if we had those books in our homes" (HIV+ Female partner, Couple #3)*

Evidence from interview conversations suggests that couples that had HIV and AIDS related books got those through donations. In addition, there was no evidence of couples using the library to access HIV and AIDS information.

The most common forms of impersonal-formal HIV and AIDS information were brochures, flyers and leaflets. Statements couples made during interviews about availability of HIV and AIDS information on serodiscordance are indication of unavailability or irregular availability of

information materials. The statements suggest that most brochures, flyers and leaflets that are available provide general information about HIV and AIDS. The male HIV negative partner in couple #17 commented that:

"The first thing is that information for cases like ours is rare. Could it be that they did research and found that if they tell people that it is possible for one partner to be positive and the other negative people will be reckless? I don't know. It is still necessary to inform people" (HIV- Male partner, Couple #17)

According the Malawi National AIDS Commission (NAC)

*"…currently [Malawi has] newsletter that target people living with HIV titled 'Overcoming'. It is produced by MANET+ with financial support from NAC. …another is the MANASO Update that is produced by the Malawi Network of AIDS Support Organization. …the Malawi Business Coalition against AIDS produces one focusing on contribution of the private sector in HIV response" (*E. Kamanga, personal communication, March, 4, 2014*)*

Evidence from my study suggests that some serodiscordant couples used impersonal-formal sources of information or information obtained from personal-formal sources in their personal-informal conversations. As presented in chapter 5 (section 5.2) some serodiscordant couples used their bodies as a source of HIV and AIDS information. When doing so, the couples used impersonal-formal sources of information or information obtained from personal-formal sources to authenticate their messages. This is demonstrated in the following interview excerpt:

"…and this book is very useful, because there are people who do not know their [HIV] status. So in my volunteer work, I visit HIV positive people in their homes. I read this book and decide who to visit on a particular day" (HIV+ Male partner, Couple #11).

Quadrant D: Impersonal – informal

Impersonal-informal sources of HIV and AIDS information were more accessible and in most cases serendipitous. A good example is music. Some couples reported to have listened to music that had HIV and AIDS information. One couple contended that some HIV and AIDS songs had information that was wrong and distressing to people living with HIV.

"Most of them are useless, these musicians and the broadcasters need to be regulated by experts, they should see how the messages are impacting people. Because you will hear a song saying; when you catch AIDS your buttocks will disappear, you have got this disease

and that's the beginning of your journey to the grave. That's threatening, my buttocks gone, and I die?" (HIV- Male partner, Couple #17)

These songs are broadcast on radios and televisions with presenters' commentary before and after the songs. Some serodiscordant couples were able to compare HIV and AIDS information from impersonal-formal and personal-formal sources with these commentaries and identify information they considered to be wrong. One couple told me:

"...there are certain things the radio announcers say which they don't mean ...those people are employed to do that ...they have not experienced HIV" (HIV+ Male partner, Couple #11).

The findings of my study suggest that there was interaction among the four quadrants. For instance, HIV and AIDS information provided by **personal-formal** sources appeared to have been obtained from **impersonal-formal** sources such as books. On the other hand, **personal-formal** sources such as doctors, nurses, and HIV and AIDS counsellors were also featured in HIV and AIDS television and radio programmes to become **impersonal-formal** sources. Similarly, most **personal-informal** sources obtained HIV and AIDS information from **personal-formal** sources such as doctors and nurses, and from **impersonal-formal** sources such as books.

6.9   How do couples appraise HIV and AIDS information sources?

During the interviews serodiscordant couples were asked to describe how they evaluated information sources at their disposal.

All serodiscordant couples mentioned the hospital as the most trusted source. However, hospital, VCT centre, ART clinic, HIV and AIDS management centre, and HIV and AIDS research centre were used interchangeably. Similarly, serodiscordant couples used the term 'doctor' and 'nurse' loosely to mean male and female health personnel respectively.

Serodiscordant couples said they trusted hospitals because they had proved their effectiveness through use. In addition, hospitals were found to be more interactive than other sources of HIV and AIDS information. Generally, hospitals in Malawi are respected for having personnel that are trained in different specialties. As such serodiscordant couples trusted information provided by hospital personnel as they considered them as experts.

One couple interviewed, despite having in their possession several information objects, could only remember HIV and AIDS information obtained from the VCT centre because of the visual aids that were used.

> *"**Male Partner (HIV-):** ….. when we went for her ART counselling before going on the new regimen, I went with her as her guardian. They told us how we can use protection as husband and wife. One, they told us so many things. ……. because I heard those, not on the radio, but a person telling us while standing there. They told us to use Chishango [condoms] and they demonstrated using some objects; a human being standing, and he was hit by arrows and at the end he fell down. This was indicating that his immunity levels had gone down. So there is immunity levels going up and immunity going down, that's what we learnt there.*
>
> ***Researcher**: Thank you, now can you describe how the experience was like hearing that information.*
>
> ***Male Partner (HIV-)**: That information; you should talk about seeing not hearing because we were seeing things happening with those objects from start to finish".* (HIV- Male partner, Couple #2)

This example illustrates the importance of blending visual and verbal features in HIV and AIDS information to maximise persuasiveness, comprehension and recall. Particularly, visual HIV and AIDS information was useful to serodiscordant couples that were illiterate. Couple #19 used the visual information in condom packaging to learn how to correctly use condoms.

> *"For example the correct use of condom, the paper shows, you can see the procedure that is there, they put images that are the same as our organs. …. the images are important because they give examples" (HIV+ Female partner, Couple #19).*

Couples that differentiated the hospital from ART clinic highlighted the interactive nature of information sessions at ART clinics as a preferable aspect. Unlike the out-patients departments of hospitals where HIV and AIDS information is also provided, ART clinics are only patronised by people who are HIV positive. This provided an assuring and safe environment. Besides, couples believed that personnel in ART clinics were themselves HIV positive or had undergone specialised training in HIV and AIDS.

Meeting other people who were infected and affected by HIV added a social dimension to the experience of HIV and AIDS information. As the following couple puts it "*at the hospital we meet*

as a group and everyone explain how they manage their illness daily to maintain a healthy body" *(Couple #13).*

It was considered obvious that when one patronises ART clinic or HIV and AIDS support groups they are HIV positive. "Participation in HIV/AIDS support groups and attendance at anti-retroviral (ARV) clinics often spark stigma and discrimination from community members" (Mgbako, Higgins, and Fenrich, 2008, p. 292). As a result some HIV negative partners find ART clinics and HIV and AIDS support groups uncomfortable.

> *"I will start accompanying him to the support group, I don't worry anymore if people will think I am HIV positive when they see me there, I know they will say 'she is positive see they are together'; it doesn't matter anymore"* *(HIV- Female partner, Couple #21).*

On the other hand, HIV negative partners who accompanied their spouses to HIV and AIDS support groups were considered spies by other members of the groups.

Serodiscordant couples expressed concern about how they were treated by people working ART centres and hospitals. There was a feeling among some couples that the maltreatment was because the health personnel working in these institutions are not HIV positive.

> *"..... so for me the carriers of the information, I want those people to be, in English they say exemplary.... I want them to be HIV positive"* *(Couple #3)*

This was corroborated by Couple #17:

> *"On that note we can also talk about reception at ART centres, it is not good. That's why you will notice that people are shunning away from ART centres"* *(Couple #17).*

The motives of people and institutions providing HIV and AIDS information were also scrutinised. A common refrain among serodiscordant couples that were interviewed was the exploitation of people living with HIV. Most couples felt that people and organisations that provide HIV and AIDS information are there just to enrich themselves. I wrote in my field notes:

> *I met two community volunteers who work with people living with HIV in Senti Township. When I explained about my study, they were not supportive. They expressed displeasure with organisations and people who come to collect names of people living with HIV and orphans but they never come back with support. They use the names to source donor funds and enrich themselves (Field notes, 22nd August 2013).*

On the other hand, hospitals, ART and VCT centres were considered to have good motives. As such, couples trusted people working in these institutions.

> *"... like the hospital, information provided is useful because I can say the hospital people do not wish us bad, they wish us well. For that reason I consider information provided by that place as important information that needs to be followed"* (HIV+ Male partner, Couple #6 separated)

Another source of HIV and AIDS information that was used by serodiscordant couples was the radio. However, couples felt radio was not interactive. Besides, HIV and AIDS programmes on the radio followed fixed and timed schedules. This meant that the couples had to tune in at that particular time and when they missed the programme they had to wait for the next scheduled broadcast.

> *"We prefer going to NAPHAM because the radio just speaks to us, we don't ask it questions, and we don't see the person speaking. But when we go there we speak to people face to face".* (HIV + Male partner, Couple #21)

Another couple said:

> *The radio sometimes talks about [HIV and AIDS] but it's too brief. At the hospital they talk step by step for a long time. On the radio they talk for a short time, the programme is over. At the hospital there are many things, they talk about this; they talk about that (HIV- Male partner, Couple #13).*

Following from the criticisms of radio as a source of HIV and AIDS information, some serodiscordant couples mentioned that they wished they had the capacity to record information broadcast on radio so that it can be listened to anytime.

Evidence from serodiscordant couples' descriptions of their experiences of HIV and AIDS information suggests that most of the issues they needed information for concerned their private lives as married couples. This was more significant especially because of the unanswered questions couples had about serodiscordance. These questions heightened the levels of suspicion and mistrust thereby threatening marriages. Against this background, serodiscordant couples' preference was for HIV and AIDS information services to be provided through home visits.

> *"It is important, like this you have come and we have met face to face, assisting us where we needed to know, at the hospital we are in a group and these issues are not discussed*

in detail. ...if you are to come again you will see that the level of interaction will be different"
(HIV+ Female partner, Couple #8)

Similarly, a male HIV negative partner who was not actively seeking HIV and AIDS information had the following preference for information sources:

"In terms of [HIV and AIDS] information I would prefer someone, when they find time, to have a habit of coming, oooh you need to do this, this and this; like reminding me so that I should not forget" (HIV- Male partner, Couple #14)

Considering that some HIV negative partners felt uncomfortable patronising ART clinics and HIV and AIDS support groups, and those that were eager to patronise these places were rejected as outsiders, it was expected that couples would prefer home visits. Home visits by HIV and AIDS counsellors would ensure that HIV and AIDS information is provided in a private environment where "*both [partners] are able to open up, and are free to talk*" (HIV+ Male partner, Couple #6 separated).

The other source of HIV and AIDS information mentioned during interviews are books. Serodiscordant couples need information sources can be used as guides when making important decisions about their health. Specific books and charts that were mentioned by serodiscordant couples during the interviews those aimed at giving people living with HIV guidance on how to manage their illnesses using home remedies.

"The way I see it is that information do come, but for brief periods, but if you have that book in your home you will be able to see; I have this problem, what is the remedy in the book. When you read you are able to do what the book is proposing and you have a healthy life".
(HIV+ Female partner, Couple #3)

Although books were mentioned as a source of HIV and AIDS information, there was no evidence of serodiscordant couples using libraries. In addition, as mentioned earlier in this section, couples that had books in their homes got them through donations.

"the books and the chart, I was a member of a support group....I was elected to be secretary as part of my responsibilities as secretary I used to travel a lot, I went to places to talk about my HIV status. So when I go to some places I could be give books; the chart I was given at Crossroads Hotel..." (HIV+ Male partner, Couple #11)

Serodiscordant couples interviewed in the study had various preferences for sources of HIV and AIDS information. Couples preferred information sources that are interactive and those that

respect their privacy. Most couples interviewed preferred home visits by VCT counsellor, nurse or HIV and AIDS volunteer. Conversation with the HIV positive partner in couple #6 revealed preference for home visits by HIV and AIDS information providers. Although the couple had been to counselling at the ART centre, they still separated.

> *"There was need for people who are knowledgeable about these things to come like you have done and talk to us. So that we both are able to open up, and are free to talk. You know, other people are able to grasp things once they are told while others are not". (HIV+ Male partner, Couple #6)*

Some serodiscordant couples interviewed appeared to only trust people who were HIV positive as trusted sources of HIV and AIDS information.

Results presented in this section suggest that serodiscordant couples' views about the quality of HIV and AIDS information were not only based on its factual correctness. Other factors were considered when appraising HIV and AIDS information sources. These included the HIV status and educational credentials of people providing the information. In addition, information sources that were interactive were appraised positively.

6.10 Information seeking and encountering by serodiscordant couples

During the interviews couples were asked to reflect back on their information seeking before the serodiscordance. Most couples conceded that they perceived their risk of being infected by HIV as very minimal because they were in a stable marriage relationship. As such they never actively looked for HIV and AIDS information. This is captured in the following conversation:

> ***Researcher:*** *My last question, I will start with you madam, before you were found HIV positive were you looking for HIV and AIDS information?*
>
> ***Female partner (HIV+):*** *I had nothing to do with those things*
>
> ***Researcher:*** *Why?*
>
> ***Female partner (HIV+):*** *I thought people that were found with the virus were those that were promiscuous, whores, yeah. So I had no time to listen to HIV and AIDS information.*

All couples reported encountering some HIV and AIDS information before one of them tested HIV positive. HIV and AIDS information was encountered on the radio, newsletters, books, newspapers, public meetings, and hospitals. Attitudes towards HIV and AIDS information were similar for most couples.

Some couples described serendipitous encounters of HIV and AIDS information which provided explanations for their illnesses. Couple #17 said:

> *"Now when reading the NAC newsletters we were noticing that the signs being described were exactly what we were seeing on this person [wife]. But we were surprised because I was always testing negative. Then in the same newsletters I read about a couple from Mzimba who had been married for 20 years, yet the wife was negative but the husband was positive. Then when I saw that I said to [my wife]; can you see this! This could be possible with us" (HIV- Male partner, Couple #17)*

In most cases, HIV and AIDS information encountered before diagnosis of the HIV infection was not used. Being HIV negative, most couples thought HIV and AIDS information was irrelevant to them. A male HIV positive partner in couple #6 provided a particularly apt description of such encounter of HIV and AIDS information.

> *"Yes, I once got information in that manner, I found people distributing booklets concerning this disease. I received one of those booklets…*

> *Of course that time I read and I was interested in reading but I did not take them seriously because I was like reading things that were not part of my life, that time" (HIV+ Male partner, Couple #6 separated)*

After one of the two partners in the serodiscordant couples was diagnosed as being HIV positive most couples started actively seeking HIV and AIDS information. Serodiscordant couples interviewed exhibited three general patterns in their information seeking. The first pattern was where both partners sought HIV and AIDS information as a couple. A good example is couple #11 where both partners were active members of an HIV and AIDS support group. In addition, both partners were community volunteers and they did some HIV and AIDS advocacy work.

> *Sometimes I go [to the support group], but remember I said I am negative. I go so that I should learn how I can live with my husband (HIV- Female partner, Couple #11)*

Secondly, other couples sought HIV and AIDS information as individuals but shared information received or encountered.

> *When I find unfamiliar information we sit down and discuss, we say 'I found this information, do you know about this?' 'No, I don't'; we need to take heed" (HIV- Male partner, Couple #8)*

The last group of couples sought HIV and AIDS information as individuals and acted as adversaries. When a female partner in couple #12 brought information about condom use from the HIV and AIDS support group she attended, the husband rejected it:

> *Male partner (HIV-): Sometimes when my wife goes to her group there are things they are told. And when she comes back she tells me; 'we have been told such and such things' and sometimes I say, isn't this woman not lying so that this should not be so.*

> *Researcher: Can you clarify what you mean by 'should not be so'?*

> *Male partner (HIV-): Like when we go to bed; they are told that we should use condoms*

This pattern was corroborated by a story told by the HIV positive female partner in couple #14. When the wife brought male condoms from the ART clinic, the husband remarked:

> *"You! can I buy candy and eat while it is in its packet?" (HIV- Male partner, Couple #14).*

Only four of the twenty-two HIV negative partners interviewed reported active information seeking before testing for HIV.

6.11 Indifference towards HIV and AIDS information

Faced with chronic illnesses that went unexplained for a long time, serodiscordant couples in this study were faced with many needs that needed information. Perceiving themselves as being at a very low risk of contracting HIV, couples responded to HIV and AIDS information with indifference. The couples were *"indifferent towards HIV and AIDS information because [they] thought that HIV is for people who are not married, who work in pubs and night clubs; [they] never thought a person in a stable marriage relationship can have HIV"* (HIV+ Female partner, Couple #8).

Indifference towards HIV and AIDS information was reflected in serodiscordant couples descriptions of their experience of HIV and AIDS information before they tested HIV positive. Couple #14 believed people who are infected by HIV are prostitutes:

> *"I only thought that people that are found with the virus are those that live dangerously, prostitutes" (HIV+ Female partner, Couple 14)*

In addition, some serodiscordant couples viewed their risk for being infected with HIV as being very low because they were in stable marriages. Similar to the excerpt from couple #14 above, couple #8 thought their risk was very low:

Researcher: Now, I want you madam, can describe what the experience was like listening HIV and AIDS information before you tested HIV positive.

Female partner (HIV+): That time before I tested HIV positive we thought people that are found with the virus are those that are reckless and not in stable relationships. (Couple #8)

As a result of this attitude towards HIV the couples were indifferent towards HIV and AIDS information:

"...therefore I didn't like, nor had time to listen to HIV and AIDS information" (HIV+ Female partner, Couple #14).

According to the couple HIV and AIDS information emphasises that HIV is transmitted through unprotected sex with multiple partners.

"But they say that one can get infected with HIV through unprotected sex. Then I thought that was the only way through which you can get HIV; sleeping with different men. Since I can't do that, then I can't be infected" (Couple #14).

While HIV positive partners transitioned into active information seeking, some HIV negative partners remained indifferent towards HIV and AIDS information. This was evidenced in interview conversations by labelling HIV counselling and information activities as their partners'. This was evidenced by the use of possessive pronouns that excluded them such as "*her counselling*" (HIV-Male partner, Couple #2) and "*but when she went for her counselling*" (HIV- Male partner, Couple #13).

On the other hand, couples confessed to have viewed HIV information as being useless. Some couples treated HIV and AIDS information as 'songs played on the radio'. A male HIV positive partner in couple #1 said:

"It was like I have listened to a song; using the messages was not there at all. The problem is that these messages are not appealing so we just listen as if a song is being played when it finished they will play another one if they want" (HIV+ Male partner, Couple #1)

6.12 Reliving HIV and AIDS information

As stated in section 6.10 some serodiscordant couples encountered HIV and AIDS information before diagnosis, which they treated as irrelevant and useless. After diagnosis the same HIV and AIDS information was relived and experienced differently.

"For me when I heard information that when you are found positive you take medication daily the rest of your life I was distressed. In fact, when I first heard it I was not distressed, but when I was found HIV positive and recalled that message I realised that this means that I will take medication daily the rest of my life, my heart was distressed" (HIV+ Male partner, Couple #1).

When this partner was asked to describe the differences between the two instances of experiencing the same HIV and AIDS information, he said:

"There is difference…I had no regard, it was like I have listened to a song and it was not necessary to use the information. … then when I was found positive I recalled that message and remembered that they were saying this, this. I developed interest to listen to [HIV and AIDS] information, reading newspapers or books on HIV to learn more…" (HIV+ Male partner, Couple #1)

Another male HIV positive partner reminiscing about HIV and AIDS related books he received before testing HIV positive explained that the information was irrelevant to him. Being HIV negative at that time, he said the HIV and AIDS information was not talking about a condition he did not have. The following excerpt is part of his reminiscence:

Of course that time I used to hear information and I was eager to read more. But in my heart I attached no importance because it was like I was reading things that were addressing issues that were remote to me at that time. But when I went to the hospital and got my test results I realised that the information has come for me and I need to receive it (HIV+ Male partner, Couple #6 separated).

Another important aspect of reliving HIV and AIDS information is where it was experienced as obscene before diagnosis. Couple #21, like other couples that were in the over 65 years old age group, viewed HIV and AIDS information as obscene and "unmalawian". The male HIV positive partner in couple #21 said:

"That time I was ignorant. When it was talked about on the radio I took it as obscenity. I realised when I was found positive that's why I am now quick going around the villages to tell people about HIV" (HIV+ Male partner, Couple #21)

6.13 Chapter conclusion

This chapter focused on understanding the needs of serodiscordant couples and the sources they use to obtain HIV and AIDS information. First, the analysis identified the unique needs of

serodiscordant couples and how these needs give rise to information needs. In general, couples'
needs were largely to manage the HIV infection and relationship. Second, serodiscordant couples
were shown to have access to various HIV and AIDS information sources. Couples were also
shown to have specific preferences for certain sources over others. Particularly, preferences and
views about information sources led to couples shunning other HIV and AIDS information
sources.

Chapter 7

Experiencing HIV and AIDS information

7.1   Introduction

As discussed in the previous two chapters, serodiscordant couples faced numerous challenges that required HIV and AIDS information. Chapter 7 will address the main research question of this study: how do serodiscordant couples experience HIV and AIDS information in Malawi. The goal is to describe the experiencing of HIV and AIDS information based on interview conversations with serodiscordant couples in Malawi. Data analysis identified thirteen themes which represent the structures of experiencing HIV and AIDS information. These are: (1) life-world, (2) serodiscordant couples' needs, (3) HIV and AIDS information sources, (4) availability and accessibility, (5) decision making guide, (6) information standards, (7) emotions, (8) denial, (9) despondency, (10) moral and religious values, (11) culture, (12) gender, and (13) social networks. 'Life-world' was identified as an overarching theme and therefore it was presented separately in chapter 5. 'Serodiscordant couples' needs' was also presented in chapter 6.

These themes will be used to build a holistic picture of how serodiscordant couples experience HIV and AIDS information within their life-world. Some of the definitions of these concepts were contextual and will be defined in the relevant sections of this chapter. First, I will present results on themes that concern the nature of HIV and AIDS information. Second, I will present results on themes on the emotional states of mind of the serodiscordant couples. The third category of themes is on results concerning cognitive states on mind, and finally I will present results on themes on social aspects of experiencing HIV and AIDS information.

7.2   HIV and AIDS information sources

As outlined in section 6.8, serodiscordant couples experienced the information sources before experiencing the information itself. The experience of information sources and personnel working in organisations that are providers of HIV and AIDS information had a bearing on the experience of the information.

As discussed in Chapter 5, HIV and AIDS information sources are part of the life world of serodiscordant couples. The couples were first concerned about the motive of the people (lived others) and institutions (lived spaces) providing HIV and AIDS information. There was a general

concern among serodiscordant couples that there were some people and institutions that exploited people living with HIV for their benefit. Couple #11 said:

> *"Some people take advantage of these things to enrich themselves at the expense of the ill. Pretending to listen to people [living with HIV] while all they want is to get rich when their friends remain poor. ... sometimes they go to support groups and pretending as if they want to support them, they get information about the support group and use it to get rich"* (HIV- Female partner, Couple #11)

On the other hand, couples felt that most people working in organisations that provide HIV and AIDS information had not experienced HIV and AIDS first hand. According to the couples, as a result these people had no empathy towards people living with HIV and they only did their job for livelihood. Couple #11 argued that some talk about HIV and AIDS such as in radio or TV drama is mere talk without the experience of disease itself.

The means by which HIV and AIDS information was delivered had a significant bearing on how serodiscordant couples perceived it. Couples were satisfied with sources that delivered HIV and AIDS information interactively. Although most couples mentioned radio as the major source of information, they were more satisfied with information obtain from ART and VCT Clinics. As stated by couple #21, in these centres couples were able to interact with personnel and ask them questions when something was not clear. One couple said:

> *"The reason why we go there is the radio just talks, I don't ask it questions, it just talks and I don't see the person talking. But [at NAPHAM] we talk to them face to face. That's why we go there"* (HIV+ Male partner, Couple #21)

However, evidence from interview conversations suggests that although serodiscordant couples preferred information sources that were interactive, many ART and VCT centres did not adequately interact with couples to answer all their questions. Some couples noted that at ART centres and hospitals they were in a group with other people living with HIV. The statement by the female partner in couple #8 is illustrative of this point:

> *"It is important, like this you have come and we have met face to face, assisting us where we needed to know, at the hospital we are in a group and these issues are not discussed in detail"* (HIV+ Female partner, Couple #8)

This excerpt exemplifies dissatisfaction with information sources that did not give individual attention to each couple. In addition, the excerpt alludes to the importance of home visits. This resonates with the life-world existential of lived others discussed in chapter 5. Serodiscordant couples preferred HIV and AIDS that was delivered to them through their interactions with lived others.

Other HIV negative partners were, as HIV negative partner in couple #1 puts it, *"always [told you] don't have [the virus]"*. Couples felt they were told what personnel in ART and VCT centres thought serodiscordant couples needed to know without listening to and answering their specific questions. As a result, questions about HIV and AIDS in general and serodiscordance in particular lingered on in the minds of the couples.

Perceptions on print HIV and AIDS information sources were in part influenced by literacy skills. Some Illiterate respondents described how they failed to benefit from print sources because they could not read. The following interview excerpt captures this finding:

> *"...because we of a low status, we don't have TV, we don't have anything, so we like to read books. But my husband can't read so I have to read to him. But for me I prefer books. Because books are readily available unless you burn them, while the radio the programme has to be on air"* (HIV+ Female partner, Couple #3)

In addition, this interview excerpt brings to fore perceptions on some HIV and AIDS information sources. Despite print HIV and AIDS information sources being not preferable for illiterate people, they are described as readily available reference points when addressing daily information needs. The excerpt also highlights the issue of cost associated with accessing HIV and AIDS information. The remark suggests that some information sources such as television are for the privileged few in society.

Another preferable feature of print HIV and AIDS information sources was described by Couple #19. Illustrations in print information were considered as important features that aided comprehension. The couple described how illustrations in a condom information sheet make it easier for them to use condoms effectively.

7.3 Availability and accessibility of HIV and AIDS information

HIV and AIDS information was described as being available or unavailable, and accessible or inaccessible. Serodiscordant couples described availability of HIV and AIDS information on two levels, first in terms of being there or not, and the second concerns the relevance of HIV and AIDS information to serodiscordance. Similarly, accessibility was described at two levels. The first level concerns ability to benefit from the information, and the seconds relates to proximity.

7.3.1 Availability of HIV and AIDS information
Within their life-world, serodiscordant couples had high expectations of some institutions to provide informational support. Most of the couples interviewed in this study were religious. As

such most of them expected to receive HIV and AIDS information from their places of worship. However, some couples reported that the churches they went to never talked about HIV and AIDS. Couple #18 said:

"In this village when we go to church, they don't talk about these things, yeah. It's all prayers not talking about HIV, as far as our priests are concerned, yeah..." *(HIV- Female partner, Couple #18)*

Similarly, a Muslim woman remarked:

"No, at the mosque they don't speak out about HIV and AIDS" (HIV- Female partner, Couple #15 separated)

As discussed in Chapter 6 (Section 6.8) in Malawi there were several newsletters produced for people living with HIV. Couple #17 described how a newsletter produced by Malawi National AIDS Commission assisted them to learn that it is possible for two partners married to each other to have different HIV statuses. The couple suspected that the newsletter was discontinued as they had not seen new issues. To confirm their suspicion I e-mailed Malawi National AIDS Commission and they said; "*The newsletter was there between 2004 to around 2007 but was discontinued following recommendations to give partners to contribute efforts in the production of newsletters. Also, the Malawi Business Coalition against AIDS produces one focusing on contribution of the private sector in HIV response*" (Malawi National AIDS Commission, E-mail communication, 4th March 2014). The Commission further said *"there is no specific newsletter that advances issues of discordant couples. Nevertheless, the Overcoming Newsletter published by MANET does cover such issues at times*" (Malawi National AIDS Commission, E-mail communication, 4th March 2014).

Couples were asked to describe the availability of HIV and AIDS information that addressed serodiscordance. Most serodiscordant couples conceded that it was puzzling to them that, given their sexual contact with each other, they had different HIV statuses. Couples stated that most of information available to them was not addressing the cause of serodiscordance.

"... you know there is a lot of information being disseminated. What I can say is that [serodiscordance] is not directly addressed. They don't explain what causes it, or what is likely to happen in future. I wish they could bring information to address this area, I wish the experts could explain clearly the causes of [serodiscordance] and what happens later" *(HIV+ Male partner, Couple #1).*

Where HIV and AIDS information on serodiscordance was available it was thought to be inadequate and superficial. In some instances, HIV and AIDS information that was available was

found to be weak in answering certain questions about serodiscordance. Most HIV and AIDS information that was available was on the general aspects of HIV and AIDS, or suitable for seroconcordant couples. Referring to a radio drama programme called *Timasukirane* (Lets open up) couple #3 described how the scene discussing serodiscordance was kept brief:

> *"....now I want to summarise, the messages, when they come, are such that they don't give us hope. Most of the information is for couples where the husband and the wife are both positive. ....I can give the example of a play called Timasukirane [Lets open up] .... I would say they somehow talk about the husband being HIV positive and the wife negative but staying together. I can give you an example; there is the Gadabwali family in there, if at all you listen to the play. Gadabwali is HIV negative and his wife Thoko is positive but they have a baby. In their family, in that play, when we listen we follow. However, that is very brief, the rest of the play is for partners that are both positive"* (HIV+ Female partner, Couple #3)

Couple #17 said that the unavailability of HIV and AIDS information on serodiscordance is an important gap that needs to be addressed. According to them this causes confusion and distress, as a result many couples break up. They said:

> *"That's why I was emphasizing that more information is needed on serodiscordance, because in many homes peoples do not realise that one partner can be positive and the other negative"* (HIV- Male partner, couple #17).

With the unavailability of HIV and AIDS information related to serodiscordance, serodiscordant couples relied on general HIV and AIDS information. However, some couples were not able to access even that information. This was evidenced by couples who had to copy HIV and AIDS information booklets using pen and paper (see Figure 7.1).
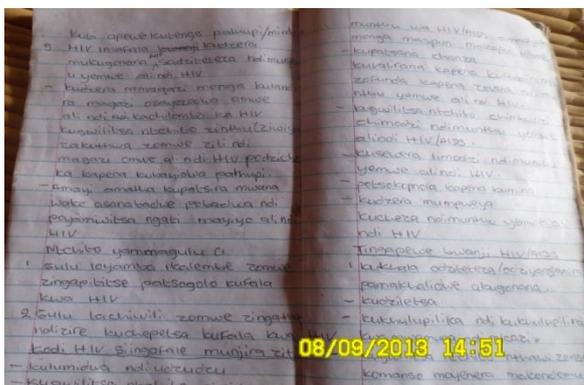
Figure 7.1: Handwritten HIV and AIDS information
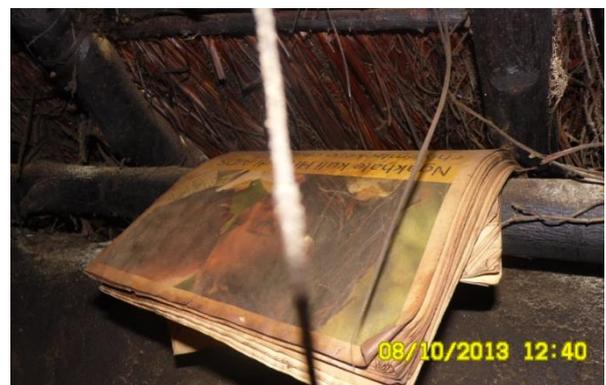
Figure 7.2: HIV and AIDS book in a kitchen roof

Almost all serodiscordant couples mentioned that HIV and AIDS information was available at VCT and ART clinics. In addition, HIV and AIDS information at these places answered some of the questions couples had. One couple told me:

"When my wife was found positive they told us that we would be given chishango (condoms) to use when having sex, secondly, they told us that when we start using condoms none of us should start sleeping around or me thinking about leaving my wife because she is positive, I will create more problems (HIV- Male partner, Couple #24).

As reported in section 7.6.1.4 serodiscordant couples described HIV and AIDS information obtained from VCT and ART clinics as encouraging as compared to that obtained from informal sources.

7.3.2   Accessibility of HIV and AIDS information

On the other hand, some serodiscordant couples were given HIV and AIDS information in formats that were inaccessible to them. Fig 7.2 shows how an HIV and AIDS book an illiterate couple received was thrown away and was being damaged by smoke and soot in a traditional kitchen. When the two examples in Figures 7.1 and 7.2 are taken together, they suggest that there is a mismatch between format in which HIV and AIDS information is provided and the needs and capabilities of individual couples. Thus, although HIV and AIDS information was available, the couple was not able to benefit from it.

Accessibility of HIV and AIDS information was also discussed with reference to the language used. HIV and AIDS information in Malawi is primarily available in English. Unfortunately, most Malawians cannot meaningfully benefit from HIV and AIDS information in English due to low literacy. For it to benefit Malawians it has to be translated into local languages. Evidence from interview conversations suggests that when some English concepts in HIV and AIDS messages are translated into local languages the messages become ambiguous. The following excerpt illustrates this:

"I don't know if it comes from the translation of English words. Most of the information that comes, if you listen carefully, is threatening. So because of fear, people stay away for fear of being associated with the fearsome group. I can give an example of ARVs, you hear they say you will be given life prolonging drugs, can you see that? So I was looking at it and said; is LA[3] a life shortening drug? It has the same purpose, life prolonging, so that

---

[3] Antimalarial drug

people do not die. As far as I am concerned, the information should talk about immune boosting. People would be encouraged and say; Oh I am going to collect the immune boosting drug, we are going to get tested, they would be encouraged" (HIV- Male partner, Couple #17)

Some couples explained that many organisations that provided HIV and AIDS information only targeted mostly people that are HIV positive. The result was that although information was available it was made inaccessible to the HIV negative partner. When organisations providing HIV and AIDS organised information events they only invited people that were infected. Therefore, HIV negative partners were not welcome. HIV positive male partner in couple #7 said:

"In terms of [HIV and AIDS] information, I can speak on her behalf. I am always worried because most of the times us who are [HIV] positive have the opportunity to attend information workshops where we learn a lot of new things about HIV, how we can protect ourselves and we can open up to each other in our homes. But am worried because I hear this information alone when my wife needed it most but she doesn't have that opportunity because she is [HIV] negative. [HIV and AIDS] information is only given to only us who are [HIV] positive…" (HIV+ Male partner, Couple #7)

Similarly, HIV negative partners who accompanied their HIV positive spouses to the HIV and AIDS support groups were rejected. Because of their HIV negative status, they were considered outsiders in groups whose members feel discriminated and marginalised. Couple #17 described their experience at the HIV and AIDS support group:

"Just to add, like in the support groups. For instance I am positive and my husband is negative, if he accompanies me to the support group, people will say he has come to spy on us. He doesn't have the virus. They forget that we are a couple and we stay together in one house therefore he is affected by the problem I have. Instead of welcoming him at the support group they say he has come to spy on us, he should go, he is not one of us, the chase him away when he could have benefited, he could have gotten some information he would use at home" (HIV- Female partner, couple #17).

This interview excerpt suggests that although some lived spaces were information rich, they were not welcoming to serodiscordant couples. In addition, this example indicates that lived spaces where HIV and AIDS information was provided only considered people that were HIV positive as their clients.

For some serodiscordant couples, HIV and AIDS information was not available close to where they lived. As such, they were required to travel to where information was available which some described as expensive. One couple told me:

> "…so I have to travel to where the book is available. The book is not available [at our local clinic] so I have to travel to the Central Hospital …to read the book and come back. For us that's a lot of money" (HIV+ Female partner, Couple #3).

Some couples in rural areas thought that HIV and AIDS services that were available in towns and cities were better that those available to them. An example of such sentiments is evident in the following interview excerpt:

> "Indeed we hear that in other places they have groups and they have activities relating to HIV. Of course we would love to participate, but how can we reach such faraway places. It's difficult, we are here in the village and those things are happening in town" (HIV+ Female partner, Couple #3).

Some serodiscordant couples described VCT and ART clinics, and nurses and counsellors in those clinics as the most accessible sources of HIV and AIDS information. Mostly these were couples that lived close to the clinics or were able to pay for transport. As presented in section 7.11 the male HIV positive partner in couple #11 described the openness of the communication they have with nurses and counsellors in VCT and ART clinics.

7.4 HIV and AIDS information as decision making guide

During the interviews serodiscordant couples reported that they faced various health problems because of the HIV infection. They were faced with issues relating to the prognosis of HIV in the HIV positive partner, management of the HIV infection, the likelihood of transmission of the virus to the HIV negative partner, nutrition, reproductive health, and many others. To negotiate their way through all these health issues serodiscordant couples needed HIV and AIDS information to make critical decisions. In addition, couples needed practical information such as on social support and how to start small businesses. All these issues required access to information.

Serodiscordant couples needed HIV and AIDS information that was specially presented to act as a 'how to' guide. One area on which couples needed guidance was on the management of HIV and opportunistic infections. With the HIV infection, HIV positive partners were vulnerable to opportunistic infections such as cancer. Therefore, HIV and AIDS information was experienced as a guide to daily living. As discussed in Chapter 5 (section 5.3) serodiscordant couples wanted to

have access to HIV and AIDS information in their homes so that they could refer to it when they face unfamiliar health problems. The HIV positive partner in couple #3 provided a good description of this experience:

> *"That book is rarely found, but it has good information. If you check inside that book you will find a page which says; if you have skin rashes you should do this, if you have sores in the genital area you should do this…. If we could have that book in our home, we would see I have this problem, according to the book what should I do with this problem. Where should I read in this book to find a solution for my problem? When you read you find that you are doing the things correctly as described in the book" (HIV+ Female partner, Couple #3)*

As indicated in section 6.6, most couples were of reproductive age. With knowledge of the risks of unprotected sex in serodiscordant relationships, couples interviewed experienced HIV and AIDS information as a guide on reproductive health. First, they needed a guide on how to prevent HIV transmission to the negative partner. The female partner in couple #19 described how they used information that is included in condom packaging:

> *"For example the correct use of condom, the paper shows, you can see the procedure that is there, they put images that are the same as our organs. .... the images are important because they give examples. When you have sexual drive, you wait for the man to be ready and it shows how to put on the condom..." (HIV+ Female partner, Couple #19)*

Second, for couples that decided to have children, they needed a guide to assist them prevent infection of the HIV negative partner and the unborn baby. Information provided at VCT, ART and antenatal clinics guided couples on the procedures to be followed when they decided to have children. As couple #20 told me:

> *"We are advised that we can do it when we see that our immunity is optimum. But we should not go beyond two weeks. After two weeks we are told to start using condoms again so that we protect the baby we are expecting from infection" (HIV+ Male partner, Couple #20)*

Evidence from the analysis of interviews with serodiscordant couples suggests that female partners were more likely to act on guidance on sexuality and reproductive health than their male counterparts. All couples that were willing to discuss the sexual aspects of their relationships reported that male partners, regardless of their HIV status, were pushing their wives either to have children or to entirely not use condoms. A more open conversation on this issue was with couple #19:

Now it's my husband pestering me that we should have another baby. I want to speak openly. My husband says I was quick to go for surgical sterilization; HIV positive people are having children (HIV+ Female partner, Couple #19).

The HIV negative partner in couple #12 did not believe his wife when she told him that at the HIV and AIDS support group they were told to use condom to prevent HIV transmission to spouses. Although the use of condoms was meant to keep him free from the HIV virus, the male HIV negative partner suspected that her wife was using this as an excuse for the couple not to bear another child. The following conversation reveals some of the suspicions:

Male partner (HIV-): Like when my wife goes to the support group, she is told some things that when she tells us that we were told this and this sometimes we say; 'maybe this woman is just lying so that we should not do it…'

Researcher: Are you able to clarify that point and give an example if possible?

Male partner (HIV-): Like when we are going to bed, ok? They are told that we should use condoms, so some of us don't understand because we are told by the woman.

In addition to not believing his spouse, the HIV negative partner in the excerpt above said he wanted that information to be confirmed by mainstream HIV and AIDS information sources.

Most couples found medication for HIV to be complicated. In addition, the changes in ART regimens created problems for some couples. Therefore, HIV and AIDS information was experienced as a guide on medication. Couple #13 used HIV and AIDS information to learn about the ART procedures:

"I encouraged her to go for counselling so that we could know the guidelines for taking ARVs, because we used to hear that there is starter pack. What is starter pack? Is it fertilizer[4]? So at the counselling they explained the medicines that are in the starter pack; Bactrim and others" (HIV- Male partner, Couple #13)

For other couples strict adherence to the guidelines for administration of ART was important so that they prevent transmission of HIV to the HIV negative partner. These couples experienced HIV and AIDS information as a guide for correct administration and management of ART:

"Only that we are eager to follow all that needs to be followed when one is on this medication, the ARVs. So we follow strictly in our home everything so that I should remain alive and not get infected" (HIV- Male partner, Couple #9)

---

[4] In 1998 the Malawi Government introduced a social support scheme consisting of free hand out of packs of improved maize seed, legumes and fertiliser to every small holder farm household in Malawi.

All couples demonstrated awareness of the importance of nutrition to the management if HIV infection. However, some couples were not able to apply the nutrition knowledge they had to local contexts. Although HIV and AIDS information that was available described, with examples, the six food groups that make up a balanced meal, serodiscordant couples needed information on the local equivalents of those foods. In addition, other couples needed information on the preparation of a balanced meal. In this context HIV and AIDS information was experienced as a nutritional guide. This experience of HIV and AIDS information is exemplified in the following excerpt:

> *"Like what they have been announcing sometime back about the six groups of food, I thought that was helpful to me, because when I take that chart I am able to see that I have eaten an egg, I have eaten nuts, or I have eaten vegetables, maybe cassava, when I put all that together I find that I have eaten a balanced diet" (HIV+ Female partner, Couple #3).*

7.5 Information standards and quality control

During the interviews serodiscordant couples mentioned many places, people and institutions as sources of HIV and AIDS information. However, couples noted that some HIV and AIDS information available from the mainstream sources was not regulated. A more telling example given was HIV and AIDS information in music. One couple told me that:

> *"The language that is used is itself threatening and as a result many people do not open up, I can assure you there are many people".*

> *"Most information in songs is useless, these musicians and the broadcasters need to be regulated by experts, and they should consider how the messages are impacting people. Because you will hear a song saying; 'when you catch AIDS your buttocks will disappear, you have got this disease and that's the beginning of your journey to the grave'. That's threatening, 'my buttocks gone', and I die?" (HIV- Male partner, Couple #17)*

Among the songs mentioned by couples were songs by Joseph Nkasa and Joe Gwaladi. Joseph Nkasa's song *Wayenda wapenga* (those that leave home don't count) had a story line of a man talking to his sister. The sister did not listen when she was advised to stop being promiscuous. *Tsiku lija pokufunsani kuti muleke chimasomaso/Achemwali munalalata kutisandutsa zidole zanu (That day, when I talked to you to stop promiscuity/my sister you were arrogant and made me look like a puppet).* HIV and AIDS information contained in these songs were found to be derogatory and threatening.

The fact that couples bought and listened to HIV and AIDS related music is evidence enough that music is a powerful tool for disseminating HIV and AIDS information in Malawi. However, HIV and

AIDS information in music was experienced as unregulated. Male HIV negative partner in couple #17 said musicians compose and record the music; and radio and TV presenters play the music without consideration of the emotional impact it would have on people living with HIV.

As discussed in section 7.3 translation of HIV and AIDS information from English to local languages led to ambiguity of messages due to lack of socially acceptable HIV and AIDS related concepts. In addition, serodiscordant couples also noted that there were no quality control measures in the design of HIV and AIDS information. This includes translation of HIV and AIDS messages from English to local languages. One couple noted:

> *"Sometimes they bring out [HIV and AIDS] information or some concepts touching on some sensitive issue before doing thorough research on it" (HIV- Male partner, Couple #17)*

And another couple suggested:

> *"When they are designing information, they should consider that the person they are targeting and the problem they have, if we tell them this how they will receive it" (HIV+ Female partner, Couple #3).*

Serodiscordant couples believed that people living with HIV were good sources of HIV and AIDS information as they have the experience of the disease. Couple #11 explained that accurate and trustworthy HIV and AIDS information comes from people who are living with HIV:

> *"People who can say the truth are ones that are suffering from this disease. But people who have never suffered, but us we know better, she knows how I suffered, what I went through. So what I will tell people will be the truth; there are things talked about on the radio which are just mere talk, those people do that as employment, they are not positive. But us who are positive are the ones who can explain the truth about this disease because we are experiencing it" (HIV+ Male partner, Couple #11)*

As observed in section 5.2, serodiscordant couples' first experience of HIV was through the lived body. In addition, this example exemplifies the belief among serodiscordant couples, and specifically HIV positive partners that high quality HIV and AIDS information should come from people living with HIV.

Though noted by only one couple, one significant observation about HIV and AIDS information was that it was evolving. Couple #7 observed that in the early days HIV and AIDS information from formal sources associated HIV infection with promiscuity. However, as the pandemic matured HIV and AIDS information became balanced to include other means of transmission.

Only that HIV information is, we can say information was different in the past, now it sounds a lot more different. Maybe now we understand it more, that time maybe we did not understand it, so there is need for people to explain things to us clearly. For example, they used to say that everyone found HIV positive is promiscuous, adulterous while now we understand more and we have confirmed that not all people that are HIV positive are promiscuous (HIV+ Male partner, Couple #6).

7.6   Emotional states of mind

The following discussion addresses emotions that were triggered by HIV and AIDS information. Gilovich, Keltner, and Nisbett (2006, p. 475) describes emotions as "brief psychological and physiological responses that are subjectively experienced as feelings and that prepare a person for action". The most dominant negative emotions were: being frightened, anxious, and feelings of vulnerability. Serodiscordant couples also experienced the positive emotion of happiness. In addition, some couples described their experiences of HIV and AIDS information which was indicative of emotions that could be classified as neutral or ambiguous.

7.6.1   HIV and AIDS information experienced with negative emotions

HIV and AIDS represented a death sentence to many serodiscordant couples. This perception was influenced by messages contained in formal and informal HIV and AIDS information. As a result, both HIV positive and negative partners experienced HIV and AIDS information with pain and bitterness.

Most serodiscordant couples observed that in many cases people living with HIV are portrayed in HIV and AIDS information as being promiscuous. HIV and AIDS information talks about unprotected sex with multiple partners as the major source of HIV infection. For HIV positive partners in serodiscordant relationships these messages suggest that they cheated on their spouses. As a result the information elicited negative emotions:

"My heart hurts because I haven't done those things. Even in our [support] group everyone says they were never promiscuous. And there also grannies, elderly people in our support group and you ask: how did these elderly people get the virus" (HIV+ Female partner, Couple #13)

This excerpt is indicative of the pain that HIV positive partners lived with. I recorded in my field notes for couple #13:

> *The support group manager confided in me that the couple separated because of*
> *accusations of infidelity soon after diagnosis of the HIV infection and they had just*
> *reconciled*

HIV and AIDS information was also experienced with bitterness by HIV negative partners. As has just been discussed most serodiscordant couples lived with suspicions of infidelity, as a result HIV negative partners experienced HIV and AIDS information as a constant reminder of the same. Evidence from interviews with the serodiscordant couples suggests that many HIV negative partners believed that *"adultery is bad because many people are getting infected with this disease because of adultery"* (HIV- Male partner, Couple #4). This perception of HIV infection appeared to eclipse the experience of the larger body of HIV and AIDS information.

> *"What I was experiencing in my heart when hearing information while trying to find out*
> *more about my wife, I was in a state of confusion, I was hurting" (HIV- Male partner,*
> *Couple #14)*

Informal-personal sources of HIV and AIDS information perpetuated messages that made serodiscordant couples to believe that they were worthless.

> *"People say a lot of things, he was found with the virus, anytime he will die, that one*
> *cannot make any investment because he has the virus. Things like those make one to be*
> *conscious of their illness and withdrawn. You are not able to participate in activities relating*
> *to this illness" (HIV+ Male partner, Couple #6)*

Transmission of the HIV virus to the HIV negative partner was a central theme in all HIV and AIDS information given to serodiscordant couples. All serodiscordant couples interviewed mentioned that they were told to consistently use condoms. Couple #1 described how information against the use of condoms given out by their church brought pain and bitterness. The male HIV positive partner said:

> *"I feel pain in my life because the things they are against are important to us" (HIV+ Male*
> *partner, Couple #1)*

Most male partners interviewed, regardless of their HIV status, confessed to have contested the use of condoms with their spouses. This attitude among male partners made women to experience HIV and AIDS information that discussed the dangers of unprotected sex among serodiscordant couples with pain and bitterness. A female HIV positive partner who was physically forced to have unprotected sex and was pregnant said:

> *"For me my heart hurts because at the hospital we are told to use condoms so that the*
> *virus should not multiply in my body, the viruses should be few....so my heart hurts*

because my friend refuses, and he doesn't want to use condoms. We always fight." (HIV+ Female partner, Couple #14)

Another female partner who was HIV negative and was abandoned by her husband described her feelings of pain and bitterness whenever she hears HIV and AIDS information stating the dangers of unprotected sex among serodiscordant couples.

7.6.1.1 HIV and AIDS information experienced as frightening

Most serodiscordant couples experienced HIV and AIDS information as threatening and eliciting feelings of fear. Some HIV and AIDS information depicted HIV as a killer. These messages might be good for people who are HIV negative and concordant negative couples but for serodiscordant they were frightening. On the one hand, HIV and AIDS information was threatening because of poor information material design skills and lack of quality control standards. One couple described how the terminology used in HIV and AIDS information elicits fear:

"I have noted that people are scared; eeeh life prolonging drugs, but if they say they are taking immune boosting drugs you will see people being encouraged; they will say my immunity will be boosted. That's the first. The language that is used is itself threatening and as a result many people do not open up, I can assure you there are many people. We have a friend; that friend is refusing to go to the hospital" (HIV- Male partner, Couple #17)

On the other hand, HIV and AIDS information is threatening because of the reality of HIV and AIDS infection. Most couples considered the fear thus elicited as necessary for the fight against the pandemic. Fear arising from information on the vulnerability of women living with HIV to cervical cancer acted as a catalyst for action for the HIV positive partner who had separated from her husband:

"The fear comes from what I hear that cancer is scary and also HIV when it develops into AIDS is scary; so when I remember the time I fell ill, am gripped with fear; I want to take these messages seriously. This information is important on my life for that not to happen to me. It is not good for me to fall ill again" (HIV+ Female partner, Couple #10 separated)

Almost all couples interviewed described the period immediately after diagnosis of the HIV infection as a time of fear. HIV and AIDS information was experienced with fear as it portrayed HIV as a deadly disease without a cure. Although this is true about the nature of HIV, it was fearful for couples that were newly diagnosed:

"That time when we hear that you could feel the soul departing, feeling lifeless because of fear; what will happen to me since they are saying that AIDS is incurable, not one will get cure once they are infected; no! Our lives were lost. It was a life of despair, we were

worried. Saying this disease has come into my home, won't my children be orphans?"
(HIV+ Female partner, Couple #24)

Interestingly, all serodiscordant couples that successfully went through this stage and started living positively with HIV said they did so because of HIV and AIDS information. In most cases information from VCT and ART centres encouraged and gave hope to serodiscordant couples. On the other hand, information from most informal sources and some public media was threatening and eliciting fear. Most couples reported to have sought or encountered HIV and AIDS information from informal sources or public media such as radio and television. This information was threatening to the serodiscordant couples. When couples went to VCT and ART centres they received HIV and AIDS information that was encouraging. A good example of this experiencing of HIV and AIDS information was provided by couple #17:

"I got encouraged after going through pre-ART counselling with her. Those sessions gave me hope, I realised that we can still live together normally and there is a chance that she will stay alive. This was contrary to information we had before which was threatening, which said when you are found positive you are done, you are going to die. And there is a song which says; When it catches you, you are dead. That time that song was playing on my mind, and I thought when found positive the next thing is death. When she tested positive that information was playing on my mind, I started giving up, my wife is dying and obviously I am also going to die. That was what was on my mind" (HIV- Male partner, Couple #17).

7.6.1.2   HIV and AIDS information experienced with anxiety

In deciding that what serodiscordant couples were describing was anxiety I relied on the context in the description. In addition to 'anxiety' serodiscordant couples used local language words that could literally be translated as 'fear' and 'complain' to describe their anxious moments of experiencing HIV and AIDS information. This imprecision of the Chichewa language is also demonstrated in the Chichewa-English dictionary (Paas, 2013).

Couples' experience of HIV and AIDS information was a continuous oscillation between anxiety and hope. Before diagnosis of the HIV infection some couples reported being anxious when one partner was presenting symptoms that matched those of HIV infection based HIV and AIDS information they had access to. Examples given by couples #17 and 8 illustrate this:

In fact for us to start suspecting that she could be HIV positive...because my wife was never ill during the first four years of our marriage, then after that she was frequently ill. Then when we went to the hospital they said it was TB...Now when reading the NAC

newsletters we were noticing that the signs being described are exactly what we were

seeing on this person (HIV- Male partner, Couple #17)

And couple #8 said:

"We decided to go for testing because of the frequent illness of my wife….We were

anxious because we were staying as a married couple like before. Whenever we heard

HIV and AIDS messages we were anxious knowing we had not tested yet we were staying

like we did before" (HIV- Male partner, Couple #8)

7.6.1.3   HIV and AIDS experienced with a sense of vulnerability

First, the experience of vulnerability was mostly described indirectly. HIV negative partners questioned HIV and AIDS information that encouraged them to stay with their spouses and wondered how they would continue to have sexual contact. Secondly, vulnerability was described directly. In such circumstances HIV positive partners explained that HIV and AIDS information that warned about the dangers of unprotected sex made them fear that they were putting their lives at risk. In addition, direct references to vulnerability were made in connection with transmission from mother to child during birth or breastfeeding. In this context, I define vulnerability as the feeling of fear of contagion (G. Green and Sobo, 2000).

As stated earlier in chapter 5 the home was considered a safe place where the two married partners felt protected from HIV. However, with the HIV infection of one partner the HIV negative partner felt unsafe and vulnerable in the home. Some women in serodiscordant relationships experienced HIV and AIDS information with a sense of vulnerability. Although they had correct information about HIV and AIDS they were not able to act on that information because it was over-ruled by their husbands. Probably a good is example was given by the HIV negative partner in couple #15. When the husband tested HIV positive he refused to use condoms and he physically forced his spouse to have unprotected sex. The wife who joined a local HIV and AIDS support group where she received HIV and AIDS information reflected on unprotected sex:

"You always hurt inside, when you think about the future and reflect on what happened;

with what I did am I okay? How will my future be? But there is nothing I can do since it

already happened but it is painful, it was not my choice, I did not agree to that, it was like

rape....I always reflect on it, were my rights respected? No, my rights were not respected.

We were two people as a couple but it is not possible to tell your friend's thoughts" (HIV-

Female partner, Couple #15 separated)

Similarly, the woman in couple #14 described how she failed to adhere to using condoms as advised by HIV and AIDS counsellors because her husband believed when one is on ART the virus is 'useless'. The husband himself described during the interview how he physically forced his wife to have unprotected sex.

HIV and AIDS information was also experienced with a sense of vulnerability by HIV positive partners. The truth about HIV is that it is incurable and fatal. When this information was received or encountered by the HIV positive partner there was a feeling of vulnerability.

7.6.1.4   HIV and AIDS information experienced with uncertainty

Because of the HIV infection both partners constantly worried about what would happen to them. However, the uncertainties of the two partners differed in some ways. First, the HIV negative partner, believing they were infected despite the negative test results were constantly waiting for the virus to come out of 'hiding'.

One source of uncertainty for the HIV negative partner was information that was provided at the VCT centre. For instance couple #18 said:

> *"When we were tested and I was found negative and him positive...I was told to wait for several months and get re-tested. I waited as advised but I was still found negative. And I was told 'Now you can now stop and wait for a year, come back a date like today next year for re-testing; because we can't say you are completely negative. It is possible that after two to three years you will be found positive'" (HIV- Female partner, Couple #18)*

Therefore, this and other HIV and AIDS information were experienced with uncertainty. As a result, many HIV negative partners regularly went for HIV testing *"because you can't live happily when you don't know your [HIV] status. You need to know your [HIV] status and then decide how to live your life" (HIV- Female partner, Couple #7).*

HIV negative partners were also uncertain about the integrity of their marriage and how they would continue sexual contact with their spouse. A good example is captured in the following conversation:

> *Female partner (HIV-): When he was found with the virus I wanted to know; like the way we are staying, sometimes I get anxious; I get scared that how will we continue having sex…*

> *Researcher: What causes that anxiety?*

Female partner (HIV-): I am anxious because I hear what people talk that it is not safe to be in contact with someone who has the virus. Even physical contact like the way we are sitting here, or even eating from the same plate; that bothers me a lot. (HIV- Female partner, Couple #21)

The HIV negative partner in couple #13 doubted the integrity of their marriage as he was suspecting that his spouse was not faithful:

"When I knew I am negative and she is positive I was suspicious that maybe my friend was cheating on me; how has this thing come into our home since I am negative" (HIV- Male partner, couple #13)

For some HIV negative partners a life time commitment to marital union with their spouse was unattainable. As a result, some couples separated.

Since HIV negative partners were constantly receiving or encountering HIV and AIDS information about the signs and symptoms of HIV infection the uncertainty was increasing. The HIV negative partner in couple #11 said:

"And when I hear there is blood testing, I rush to get checked. May be that time the machine missed [the virus] or maybe something has happened. But I am found, in many places, I am found in many places because of encouragement from my husband" (HIV- Female partner, Couple #11)

The phrase 'maybe something has happened' is indicative of the sense of uncertainty the negative partners lived with.

Similarly, couple #8 encountered HIV and AIDS information from friends which created uncertainty.

"If you talk about distressing messages, when we in a group other people can this and that, 'if one is found with the virus, that person is dead, they do not have a long life'. Such talk distresses us, does it mean we are dead?" (HIV+ Female partner, Couple #8)

As noted in the previous chapter, many serodiscordant couples were religious. In the absence of scientific solutions to the HIV pandemic most serodiscordant couples found hope in religion. HIV and AIDS information provided by most religious institutions addressed uncertainty arising from HIV infection. Although couples did not believe some religious messages such as about divine

healing of HIV, religion gave them hope for the future. In addition, religious HIV and AIDS information attempted to explain HIV and AIDS as the will of God.

> *If we are strong today it's because of religion, even for us to open up like this it's because of religion... He told me that God knows everything that happens to you, sometimes illnesses come because we are naughty, and sometimes they come by God's plan so that you do not stray away. I remember he told me that it is possible that if you didn't have this illness you would have departed from God's way. You would be saying everything is alright. But when there is something you always say eeeeh let me stay in here, the greatest reward is waiting for me. He also told us that, spiritually, it is possible to be healed with prayer, but it is not everyone because God's grace is not demanded. It doesn't mean that if this one got healed then I can also get healed, no! you can't ask for grace, it is a gift. So our Pastor enlightens us on such issues. Little by little we gained strength up to now, we don't fear and we are not ashamed any more (HIV- Male partner, Couple #17)*

In addition, HIV and AIDS information provided by ART and VCT centres was said to counter the uncertainty created by HIV and AIDS information from some formal and informal sources. Most serodiscordant first experienced HIV and AIDS information that elicited fear and created uncertainty.

> "*Yes, they were just talking; saying that when someone is HIV positive we should avoid getting closer to them because they can transmit the virus to you. That distressed me because I eat from the same plate with my husband. But when we went to the hospital it's where I got correct information, they told us to avoid stigma, I should protect myself in bed. When making love we should use protection, we should put on a condom*" (HIV- Female partner, Couple #21)

Similarly, couple #17 was surprised that HIV and AIDS information that was provided at the ART and VCT centres was different from that available from informal sources. The couple, referring to songs with threatening messages (interview excerpt in sections 6.8 and 7.5) said:

> *Maybe those messages are good for people who are negative so that they should be careful, but for someone who is already positive the message can contribute to the speedy dying of that person (HIV- Male partner, Couple #17).*

The results presented in this section are consistent with those on lived time in section 5.4. Most serodiscordant couples believed that their life-span was truncated. Therefore, they were uncertain

about the future. This section has also highlighted the contribution some HIV and AIDS information made to this uncertainty.

7.6.2   HIV and AIDS information experienced with positive emotions

Despite the many negative emotions with which HIV and AIDS information was experienced many couples reported to have experienced some information with happiness. Many HIV positive partners reported using HIV and AIDS information to make important health decisions.

Most women in serodiscordant relationships who were pregnant or had just given birth said they experienced HIV and AIDS information with happiness. As discussed earlier in section 6.6 women, regardless of their HIV status were pressured into getting pregnant by their spouses. However, HIV negative women feared they would get infected and HIV positive women were worried that their viral load would increase if they engaged in unprotected sex. These fears were allayed when they received or encountered prevention of mother to child transmission (PMTCT) information. In addition, what they learned from PMTCT information assisted couples to plan for bearing a child and for the female partner to satisfy the desires of their husbands. The female HIV positive partner in couple #12 commented:

> *"Sometimes my husband tells me; 'my wife, I want us to have a baby'. But when I go to the support group we are taught different things, they tell us that people that are HIV positive should not bear children. Sometimes I am encouraged when I hear on radios; they say that HIV positive people can bear children with guidance from the hospital" (HIV+ Female partner, Couple #12)*

HIV and AIDS information was also experienced as encouraging and liberating. All serodiscordant couples mentioned the ART or VCT centre, and the church as places where they received HIV and AIDS information that was encouraging. Before the diagnosis, most couples reported to have either received or encountered HIV and AIDS information. Although that information was considered useless or irrelevant at that time, it was re-lived and found to be threatening after diagnosis. Before the HIV positive partner could start antiretroviral treatment, the couple was required to undergo counselling where they received HIV and AIDS information which was considered to be encouraging. Couple #17 described their experience:

> *"I got encouraged after going through pre-ART counselling with her. Those sessions gave me hope, I realised that we can still live together normally and there is a chance that she will stay alive. This was contrary to information we had before which was threatening,*

which said when you are found positive you are done, you are going to die" (HIV- Male partner, Couple #17).

Information on the efficacy of ART was also experienced with positive emotions of happiness and hope. As compared to HIV and AIDS information from everyday talk and music, information from ART clinics and VCT centres was describe as encouraging.

"…because when he was found positive we went together, at the beginning we were so worried but when we went to the hospital they encouraged us, now we just live, encouraged. I even encourage my husband to take his medication" (HIV- Female partner, Couple #1)

7.6.3   HIV and AIDS information experienced with ambiguous emotions

If we consider emotions to be on a continuum with negative and positive emotions as the extremes, some serodiscordant couples experienced HIV and AIDS information with emotions that would be placed in between. Some partners interviewed in this study appeared not to be bothered by being in a serodiscordant relationship. Responses like "*I know that AIDS came for everyone*" (HIV- Female partner, Couple #23) and "*even if I get bothered, it happened*" (HIV- Female partner, Couple #20) suggest that for these partners HIV and AIDS information did not trigger any classifiable emotions.

A male HIV negative partner in couple #24 also did not show or describe any emotions that could be classified as positive or negative. Being of the older generation, the partner claimed that he had heard about plagues that occurred in years gone by and believed HIV was one of those. He said:

*"We think that it's a plague because of how this disease started, I hear it's the whole world. When I think about it I am convinced it is just a plague" (*HIV- Male partner, Couple #24*)*

He further described another plague of famine that came and went in 1949 suggesting that this one too will go.

7.7   Cognitive states of mind

Evidence from my study suggests that some emotional states of mind outlined in section 7.6 caused some cognitive states of mind that will be presented in this present section. Cognitive processes are "mental processes underlying our ability to perceive the world, remember, talk about and learn our experiences and modify our behaviour accordingly" (Andrade and May, 2004, p. 1).

7.7.1   HIV and AIDS information experienced with denial

Walker, Payne, Smith, and Jarrett (2004) define denial as a coping mechanism when people are faced with uncontrollable situations. Although denial does nothing to improve the controllability of the situation, it minimises the threat posed by the situation.

Some evidence of denial was identified among couples that had just been diagnosed with HIV infection. During the interviews these couples would start by giving the impression that they were not bothered by the HIV infection. However, as the interview matured and with probing the couples admitted their fear and anxiety. At the beginning of the interview with couple #18, the female HIV negative partner said:

> *"Aaah now there is no problem at all; am not the first one. There are many people, and now I no longer worry" (HIV- Female partner, Couple #18)*

In the course of the interview she came back and admitted that she is always anxious about the probable death of her husband and the future of the children. She said:

> *But will my husband and I live a long life to bring up our children, how can we look after our children since my husband has the virus maybe he can die today? (HIV- Female partner, Couple #18)*

And I probed:

> *Researcher: That means you are anxious about that*
>
> *Female partner (HIV-): Yeah, that will I manage to look after the children alone, but we need to know how my husband's life will be.*

Couple #18 had just been diagnosed with HIV infection and the marriage nearly collapsed. The interview conversation therefore is indicative of an attempt to minimise the magnitude of the problem at hand.

Another couple did not mention about their separation after the female partner was diagnosed with HIV. Although, another reason could be that the couple might have considered this information too personal to be disclosed to a stranger, some statements made by the couple during the interview suggested otherwise. Throughout the interview the HIV negative partner gave the impression that he accepted the HIV test results for his partner and they are a happy couple. However two statements by the two partners suggest otherwise. The male HIV negative partner said:

"When I knew I am negative and she is positive I was suspicious that maybe my friend was cheating on me; how has this thing come into our home since I am negative" (HIV- Male partner, couple #13)

And the female HIV positive partner remarked:

I am supposed to; since my friend is negative and I am positive, I am supposed to, when I find HIV and AIDS information, share with him so that he is encouraged in his life (HIV- Male partner, couple #13)

However, the HIV and AIDS support group manager from where I recruited the couple commented about the couple and I recorded in my field notes:

The Manager of Chinsapo HIV and AIDS Support Group told me that the couple fights a lot over the HIV infection. The couple once separated and it the intervention of the manager for them to reconcile (Field notes, 28th September 2013).

My analysis of data also suggests that denial was also caused by the shame that was attached to HIV. Evidence from interview conversations appears to indicate that people living with HIV were considered to be promiscuous and unfaithful to their partners. The following interview excerpt provides evidence for this finding:

"...because I have never done such things, they say that you can catch the virus through borrowing razor blades, even at traditional doctors they can use one razor blade to make incisions on several people. So even when people talk, I am not worried because I never did those things" (HIV- Female partner, Couple #13)

Only one HIV positive partner openly mentioned that she was infected through sexual contact with other men. All other couples mentioned other means of HIV and AIDS transmission. However, this appeared to be denial because when probed or when responding to other questions HIV negative partners conceded that they were suspicious of the spouses. A good example is the exchange between the two partners in couple #4 quoted in section 6.5. The female partner was insisting that she got infected through unsterilized birth control injections while her spouse believed it was through sexual contact with other men.

Another example of denial that was caused by the shame of being HIV positive was provided by couple #13. At the beginning of the interview, the male partner said he believed his wife might have been born with the virus. However, later in the interview the husband confessed to have been suspicious of his wife (section 7.7.1).

172

These two examples suggest that despite serodiscordant couples being aware of sexual contact as one of the possible means of HIV transmission, they chose to rule it out because of the shame attached to it. Thus, most couples avoided the shame by explaining the HIV transmission as having resulted from transmission means they considered to be socially acceptable.

7.7.2　HIV and AIDS information experienced with despondency

The period immediately after discovering their HIV status represented a time for re-orientation for serodiscordant couples. One interesting trend in the information behaviour of serodiscordant couples was the transition from denial to accepting their illness. At the same time the couples appeared to continuously oscillate between anxiety and hope. In addition, there is evidence that HIV and AIDS information facilitated this transition from denial to acceptance of illness, and was also responsible for the anxiety and hope experienced.

In addition, knowing that they would be in sexual contact with an HIV positive partner and a possible source of HIV infection made the HIV negative partner despondent. A male HIV negative partner in couple #17 described what suggests that he felt trapped and defeated. He said that he had listened to HIV and AIDS songs which stated that "*When it catches you, you are dead*". Therefore, when his wife was found positive he felt defeated. The most common refrain among serodiscordant couples was the need for HIV and AIDS information that would give them hope for the future.

> *"I don't need anything; I only need information that can encourage me, like that message which says that HIV is not the end of life but a new life into the future. I need such encouragement to face the future" (HIV- Male partner, Couple #12)*

This interview excerpt suggests that when some information needs are not met serodiscordant couples were hopeless and despondent.

As presented in section 7.6.1.4, HIV negative partners experienced uncertainty when they were told that their negative HIV status could be temporary as the virus could have been hiding. That uncertainty appeared to have caused feelings of despondency in some HIV negative partners. One respondent told me that she believed that she was infected, and the hospital kept telling her she was negative and delaying her 'treatment'. She said:

> *"Am so worried that when I go to the hospital they always say am negative. How then will I get treated, maybe I have the problem, but when you go they say; 'No'; sometimes when they see your records they just send you back without testing you. They say; 'there is no need to get tested'. Sometimes I make plans to change my identity, to elude the system*

and get tested. I always worry about this. I am in great trouble" (HIV- Female partner, Couple #16)

When I talked to her I could sense her desperation to be treated for the illness she believed she had. She was dejected because she could see evidence of the efficacy of ART on her husband.

As outlined in chapter 5 (section 5.4), most serodiscordant couples felt their life span was truncated and death was imminent. These feelings were reinforced by both formal and informal HIV and AIDS information. Specifically, most couples reported that everyday conversations with friends and relatives stressed the deadly nature of the disease and the devastation it inflicts on families. HIV and AIDS information from such sources created despondency among serodiscordant couples in general and in particular HIV positive partners. For instance, the HIV positive partner in couple #3 heard a doctor talking about the possible death of people due to lack of medication:

> *"When I went to the hospital, that day we were treated by a doctor who was not living with HIV (a sigh of disappointment) then the doctor came out into the waiting room and he said; 'All women with children here, you will die, the President is failing to buy medicine, for this reason you will all die' so for me I received this information because it was coming from a doctor, if government appointed him to be a doctor then they knew he can tell me useful information" (HIV+ Female partner, Couple #3)*

Similarly, couple #8 encountered HIV and AIDS information from friends which made them feel despondent about the future.

> *"If you talk about distressing messages, when we in a group other people can say this and that, 'if one is found with the virus, that person is dead, they do not have a long life'. Such talk distresses us; does it mean we are dead?" (HIV+ Female partner, Couple #8)*

Results presented in this section suggests that HIV and AIDS information that insinuated that people living with HIV are dead caused serodiscordant couples to be uncertain about the future. The uncertainty made the couples to question the reason for investing into a future that will not happen. Perhaps the HIV positive partner in couple #17 summarises it all:

> *"All these coupled with the message that these are life sustaining; then you tell yourself oooh sustaining life, what do they mean, does it mean my life ended and they are just supporting me to stay alive? So that I can stay a little longer? Even investments are meaningless when I know I am already dead, my life is sustained by medicine and I will die*

anytime. Now when you fall ill, even a mild headache it reminds you of your impending death, a little pain is a reminder that my life is sustained by ARVs. You live a hopeless life" (HIV+ Female Partner, Couple #17)

7.8 Moral and religious aspects of experiencing HIV and AIDS information

Religion assisted couples to transcend their human limitations in dealing with HIV and begin to believe that God can take away their anxiety. Assertions like "*I leave all in the hands of God*" or "*we just look up to God*" (Couple #8) were indicative of couples' admission of limitations of human capabilities. Although serodiscordant couples knew that there was no medical cure for HIV infection, some still believed that divine healing was possible. One HIV positive partner remarked that:

> *When I compare the Bible with this world I reach a conclusion that this world has no tangible solution but the Bible or let's say in heaven there is a solution. This means that this world has no cure for AIDS but God has since He is the creator (HIV+ Male Partner, Couple #11)*

One couple reported that they experienced HIV and AIDS information provided by their church with guilt of sin. Although the church was against condom use, the couple decided to defy the church laws because, they said; "*we think we are protected when we use condoms*" (HIV+ Male partner, Couple #7). However, when other people living with HIV claim to have been healed by prayers the couple feel they are not because of sin arising from condom use. As such they reported that they experienced HIV and AIDS information provided by the church with guilt as sinners:

> *"Why do other people say my God has healed me? My God has saved me? How are they healed? Maybe we are not healed; we are not saved because God is angry because we use things He does not allow"* (HIV+ Male partner, Couple #7).

Serodiscordant couples interviewed in the study believed that on moral and religious grounds condom use among married couples was inappropriate. Couple #7 believed that when God instituted marriage He did not intend partners to use condoms. Therefore, HIV and AIDS information that promoted the use of condoms among serodiscordant couples was viewed as going against God's plan for marriage. The couple said:

> *Sometime ago there came people to conduct prayer meetings and they said that a human being was not created to use condoms. Because we do that thing as a married couple, sex in marriage is done by authority from God and it is not necessary to use condoms (HIV-*

Female partner, Couple #7*)*

The morality of the information providers also came into question when experiencing HIV and AIDS information. Many serodiscordant couples believed that international donor organisations were providing a lot of funding to assist people living with HIV but the resources were abused by people and organisations that claimed to work for affected and infected people. Some couples were even suspicious of my motive in conducting this study. Of couple #14, I recorded in my field notes that:

> *After the interview the male partner confessed that he did not want to meet me because he was fed up with people and organisations that swindle people living with HIV* (Field notes, 28th September 2013)

Interestingly, some HIV and AIDS community volunteers that were contacted to assist in recruitment of serodiscordant couples showed signs of expectations of economic gains. They indicated that they would work for me if I had plans to implement HIV and AIDS related projects in the area.

Some serodiscordant couples viewed some HIV and AIDS information as too explicit to be provided to children. With this perception, these serodiscordant couples thought it was morally wrong for HIV and AIDS information they considered explicit to be broadcast on the radio. Consequently, most couples said they avoided HIV and AIDS information because they considered it obscene. As presented in section 7.5 couple #21 described how before testing HIV positive they ignored HIV and AIDS information broadcast on the radio because they were considered obscene.

Another aspect that was highlighted by serodiscordant couples was judgement of behaviour. HIV and AIDS information, formal and informal, was experienced as being judgemental of the couples' moral standing in society. For some HIV positive partners it was the spouses who were the first to make judgemental statements.

7.9   Culture and experiencing HIV and AIDS information

Experience of HIV and AIDS information can best be described within the cultural milieu within which it was experienced. All serodiscordant couples that participated in the study were indigenous Malawians with strong cultural roots. Some couples described how their illnesses were culturally explained. They believed that "*people from the village are causing him to be ill; maybe his mother or his father is bewitching him*" (HIV- Female partner, couple #7). Others thought ancestral spirits "*wanted to give me prophetic powers*" (HIV+ Male partner, Couple #20).

These cultural beliefs in turn made couples not to believe HIV and AIDS information and turn to traditional doctors instead of the hospital. Couple #13 confessed: "*we reached the extent that we went to a traditional doctor, the traditional doctor was just deceiving us*" (HIV- Male partner, Couple #13).

Culture also played an important role in the acceptability of HIV and AIDS information. Some serodiscordant couples, especially of the older generation, found HIV and AIDS information to be too explicit and not suitable for public media. They said that *"information that is given out now is different from that which was given out in our time. In those days there was no discussing obscene things on the radio. Those things were discussed in private"* (HIV+ Male partner, Couple #21). In addition, HIV and AIDS information was blamed for promiscuity among young people:

> *"They are too explicit, the problem is that children will copy and try out what is said, because in our days there were no such things, talking obscene things anyhow, that is indecency" (HIV- Male partner, Couple #9)*

However, other couples observed that due to severity of the HIV pandemic, it was necessary to inform people using whatever language in order to save lives.

Only one female HIV positive partner described how being married in patrilineal family system affected her management of the HIV infection. This woman was abandoned by her husband after her HIV test came out positive. Although the husband left, she said; "*culturally he is still my husband because he paid the bride price*" (HIV+ Female partner, Couple #10 separated). On bride price she said; "*the husband thinks he had bought you, you are part of his family and you can't just leave. It's like he has bought you and he can do anything with you*" (HIV+ Female partner, Couple #10 separated). Bound by these marriage cultural practices, the female partner in couple #10 did not have the freedom to act on HIV and AIDS information when she was with her husband. This is revealed in the following statement:

> *"Now it's good that I am getting counselling while I am alone so that I can adhere to what I am told….the cruelty I suffered makes me doubt that if he were here with me he would listen to [HIV and AIDS] information, put it into practice and take care of each other"* (HIV+ Female partner, Couple #10 separated)

Interview conversations with many serodiscordant couples provided evidence that suggests that men had a privileged position of power in marriages. There was evidence in many assertions of male ego based on the cultural position of men in society. For instance, the female HIV positive partner in couple #14 described how she fought with her husband when he was refusing to use condoms. In the interview the husband remarked:

"then in the bedroom when I tried to make advances on her she would reject me and want to bite me. But you know a man is a man and the strength of a woman is very little, it all resulted in [pregnancy]" (HIV- Male partner, Couple #14)

Similarly, another male HIV negative partner said:

"...when you know that this is your wife you should teach her that I am the man and she is a woman" (HIV- Male partner, Couple #19).

These two examples suggest that when two partners in a serodiscordant relationship did not agree on a subject relating to HIV and AIDS information, the husband's opinion took precedence. In addition, this presents evidence of physical coercion to disregard HIV and AIDS information in some couples. Some serodiscordant couples separated after the diagnosis of HIV infection. I recorded in my field notes:

"Kanengo AIDS Support Organisation had serodiscordant couples on their register. However, in most serodiscordant couples the women were HIV positive. The women were tested at antenatal clinics, when the husbands were tested and found negative all couples separated" (Field notes, 28th August 2013)

Many couples reported that they experienced HIV and AIDS information with fear of possible separation from their spouse. One couple which had just discovered that they were serodiscordant at the time of the interview confessed that they were struggling to stay together while confronted with HIV and AIDS information that said that HIV is largely transmitted through unprotected sex.

"Learning about his HIV status was a distressing experience. At that time I was very worried since one was positive and the other negative.....at that time our marriage was surely shaken; 'let's go our separate ways, you are positive and I am negative', yes. Now I want to know more, I want to join support groups to meet people like you to explain to us" (HIV- Female partner, Couple #18)

Two women and one man interviewed in the study were on separation from their spouses. One woman's HIV positive husband left after she insisted that they should consistently use condoms as advised at their counselling session. The second woman's husband left after she disclosed her HIV status to him. A man, who was on separation from his wife, reported that he was convinced that he was infected by the wife. They went for VCT after suffering from syphilis and the husband was found HIV positive and the wife HIV negative. The wife left and never returned. Another woman experienced a 3-month separation with her husband after she tested positive, and she

came back after her parents talked to the husband. These partners said that HIV and AIDS information was a reminder of separation from their spouses:

"When I hear HIV and AIDS information my heart is touched. When they talk about those things am reminded of what my wife did; leaving home, running away. It reminds me how things happened that time, saying oh if my wife had follow this she would have not run away" (HIV+ Male partner, Couple #6 separated)

Married couples are expected to bear children for a man to prove his masculinity. A good example was given by an HIV positive male partner whose wife had a child from her previous marriage. "Her relatives expected that I would have a baby" (HIV+ Male partner, Couple #6 separated). However, because of the HIV infection the couple was advised to use condoms. This meant they would not have a child and the woman left. This resonates with the discussion about lived body as a child bearing body in section 5.2.

Some couples found the local language terminologies used in translation of HIV and AIDS information from English to Chichewa as socially unacceptable. Couples that felt this way were those in the age group of over 65 years. For instance, couple #9 said that the content of some HIV and AIDS information is not suitable for broadcasting on the radio in the presence of children.

"I am talking about like what they do on the radio, they literary talk about how to make love. When making love do this, do this; that is not good at all. That information should be provided at the hospital, like we are talking here in private, we are free and open. Not on the radio, talking while children are listening, that's not good" (HIV- Male partner, Couple #9).

During the interviews I observed that most serodiscordant couples were using figurative language and proverbs for expressions they thought would be explicit. Figurative language and proverbs were used when making reference to issues of sexual nature, human genitalia and pregnancy. For example, a male partner in couple #12 used the word 'sleeping' to refer to sexual intercourse, and 'protector' for condom. Similarly, male partner in couple #19 used an expression 'a man should not be slow' to mean 'a man should reach orgasm first'. In some interview conversations, it took careful probing to decipher the meanings of such language usage.

7.10 Gender

Gender is a cross-cutting theme throughout this chapter. Evidence from interview conversations suggests that the gender of a partner in a serodiscordant relationship was an important factor in the experiencing of HIV and AIDS information. Some couples argued that it was easier for women

to go for HIV testing. Besides, when women are pregnant they are encouraged to get tested so that the unborn baby is protected if the woman is HIV positive. The HIV positive partner in couple #17 claimed:

> *"...it is usually difficult to get a man to go for testing. For women it is easier, whether you like it or not once you are pregnant it is mandatory for you to get tested. Now when the husband finds out that his wife was found [HIV] positive, that's the end of the marriage" (HIV+ Female partner, Couple #17).*

Consistent with this claim, evidence presented in section 7.9 indicates that only women were chased from the home when found HIV positive. When men left, they did so voluntarily. On other hand, some women who stayed in the home with their husbands were forced to ignore HIV and AIDS information obtained from ART or VCT centres, and HIV and AIDS support groups. In section 7.6.1 I presented examples of women experiencing HIV and AIDS information with bitterness because their husbands forced them to have unprotected sex.

Female partners in serodiscordant couples were also not able to negotiate safer sex because of male ego of their husbands. In section 7.9 I reported the attitude among some men in serodiscordant relationships who looked down on their wives.

On the contrary one male HIV partner argued that HIV and AIDS information over-emphasizes problems faces by women ignoring the maltreatment faced by men. He claimed that culturally men are expected to be strong and men who report HIV and AIDS related gender based violence are labelled as being weak. In addition, he reported that when he suffered gender based violence because of his HIV status there was no informational support for him. He said:

> *"In my case I always get worried because like on the radio issues faced by men are not addressed, men are not given a voice to talk about gender based violence. When women face gender based violence it comes out very easily but when men speak out they are ridiculed. This is also violation of our rights..." (HIV+ Male partner, Couple #6 separated).*

7.11 HIV and AIDS information experienced in social networks

The two partners in serodiscordant relationships experienced HIV and AIDS information as spouses. Although they had different HIV statuses, the life worlds of the two partners were intertwined so too were their experiencing of HIV and AIDS information. Because of the nature of HIV and AIDS information needed by both partners they were required to share and act on it as a couple.

First, when testing partners were encouraged to go together. As stated by couple #18, partners that tested together received counselling together:

> "When we went for testing my husband was found with the virus and we were counselled" (HIV- Female partner, Couple #18)

If one partner was found HIV positive after going for testing alone, they were advised to go back with their spouse.

> "I went to the hospital, when the doctor saw me he said I should be tested.... I was found with the virus. When I came home I told my husband, because I was advised to ask him to go for testing too. When I told him, he said he can't go" (HIV+ Female partner, Couple #14).

Stories told by couples during the interviews suggest that the two partners' lives were intertwined so much so that when one partner tried to make decisions about HIV and AIDS information it caused distress on the other partner. One such story was told by couple #17. After testing HIV negative the husband did not believe the results and unilaterally decided not to use condoms because, according to him, he was already infected. He said:

> "Last year when we went to …[the] office for the training my wife opened up and told people that; 'my husband has been refusing to use condoms and it hurts me'. Can you see, all along I thought things were alright between us, not knowing that my partner was hurting. So we started to use condoms again last year and I thought I should re-test before starting using condoms" (HIV- Male partner, Couple #17).

Beyond the serodiscordant family unit, meanings of the experience of HIV and AIDS information were also created through interaction with other people in the community. Couples occupied lived spaces that were also occupied by other people who experienced HIV and AIDS information. In these spaces serodiscordant couples had conversational relationships with others through which the experience of HIV and AIDS information was facilitated. First, there were conversational relationships with people working in hospitals, VCT and ART centres. HIV positive male partner in couple #11 describes the relationship:

> "Like at [the hospital], when we go to collect medication, there is openness with the nurses, we are able to ask them any question we want" (HIV+ Male partner, Couple #11)

At the hospital, VCT and ART centres HIV positive partners shared, discussed and interpreted HIV and AIDS information with other people living with HIV. In some cases, the HIV negative partner accompanied their spouse to these places or went alone to collect medication on behalf of their spouse. As presented in chapter 6 (section 6.10) there appeared to be three general patterns of experiencing HIV and AIDS information among serodiscordant couples. These are:

the two partners experiencing information as individuals but sharing information, the two partners experiencing information as individuals and acting as adversaries, and the two partners experiencing HIV and AIDS information together as a couple.

All serodiscordant couples that were interviewed were living in communities where they occupied different lived spaces with other people. In these spaces couples either experienced HIV and AIDS information or engaged in conversations that shaped their experience of HIV and AIDS information. Some people who occupied the lived spaces together with serodiscordant couples were also living with HIV and they acted as sources of experiential HIV and AIDS information. Evidence from interviews suggests that these sources had a positive influence on serodiscordant couples. For instance the HIV negative partner in couple #22 said:

> *"I heard that she was on ART, she was found [HIV] positive. Then I talked to her; …She told me; 'Don't be distressed, that's very minor, just follow the advice you got from the hospital'. I said; 'really?' He explained everything and from that time all my worries were gone" (HIV- Female partner, Couple #22)*

Similarly, the HIV negative partner in couple #14 who sent his wife away after diagnosis was positively influenced by a friend who was living with HIV:

> *"While we were talking he told me that; 'I am on ART and I just accepted it, even my wife', in his case the wife is negative. ... So I asked him in a disguised manner, I said; 'what happened?' and he told me; 'my wife just accepted it, it happened and there was nothing to do about it'. From that time.....I just accepted" (HIV- Male partner, Couple #14).*

However, other people who occupied lived spaces with serodiscordant couples in their communities had negative influence on their experience of HIV and AIDS information. Although all serodiscordant couples interviewed were religious, some HIV and AIDS information provided by some religious leaders and institutions were found to contradict HIV and AIDS information from official sources. HIV and AIDS information from some religious institutions were discouraging serodiscordant couples from using condoms and taking ARVs. This conflict was noted in the following excerpt:

> *Now in Catholic I find that HIV and AIDS information that is provided contradict because Catholics do not allow using condoms. Our church teaches that, it is sin to use condoms (HIV+ Male partner, Couple #1)*

Because of the nature of the illness, many couples desperately looked for means by which their HIV infection could be healed. Serodiscordant couples were aware that conventional medicine could not heal their infection and they turned to religion for divine healing. Religious institutions provided social networks through which HIV and AIDS information was experienced. However,

some couples doubted the authenticity of some of the healing claims made by some church leaders. "*Can a person be healed by someone's words? No, they can't be healed. Only if they go for testing to prove they are healed*" (HIV+ Female partner, Couple #10 separated). Couple #9 was asked to describe their experience of HIV and AIDS information in religious institutions:

> *"They say; 'You are healed, stop taking your medication'. I can't stop, even my children, I tell them not to stop. Yes, God is there in heaven but you can't stop taking medication, it's for life. I have seen men and women dying after being told stop taking medication, you are healed in Jesus name. With faith adhere to medication; it's your life" (HIV+ Female partner, Couple #9)*

Some couples felt insulted by some HIV and AIDS related messages provided by some religious institutions. The HIV positive partner in couple #17 was told that she had HIV because she was a sinner. She described the experience:

> *"When he said we are sinners, it was painful, yes I used to be promiscuous, but now, even God can forgive any sin, I pray to God to forgive me so that I should follow His truth and see what I can do, and this one is telling me all this trash. I was demoralised; that makes one to lose interest and stop fellowshipping with them; discouraged because of his messages" (HIV+ Female partner, Couple #17).*

Couple #17 described how they had witnessed transition in several churches from delivering negative messages to positive and encouraging messages. This was attributed to availability of HIV and AIDS information to religious leaders and first-hand experience of HIV by many pastors. They said:

> *This is changing now, pastors because pastors have access to correct information, they also have forums where they teach each other about HIV and AIDS and many pastors now know the truth about AIDS (HIV negative Male partner (speaking in the background): And there are pastors that are HIV positive and have experienced it first-hand) (HIV negative Female partner, Couple #17)*

On the other hand religion facilitated a positive experience of HIV and AIDS information for some couples. As stated by couple #17, religious leaders that were well informed or were living with HIV provided information that gave serodiscordant couples hope for the future. At institutional level some religious organisations were active in supporting people living with HIV by setting up HIV and AIDS support groups. Three of the couples that were interviewed in the study were recruited from an HIV and AIDS support group established by a religious organisation.

7.12 Chapter conclusion

The aim of Chapter 7 has been to describe how serodiscordant couples experience HIV and AIDS information. The descriptions are contextualised by the life world existentials that were described in Chapter 5. This present chapter commenced with a description of how serodiscordant couples experienced information sources.

Chapter 7 also draws attention to serodiscordant couples' emotional states of mind and cognitive states of mind that are caused by HIV and AIDS information. The chapter concludes with a presentation of cultural, religious, moral and gender issues that impact on the experiencing of HIV and AIDS information.

The results of this study presented in chapters 5, 6 and 7 will be distilled in chapter 8. This synthesis will serve two purposes. First, it is aimed at developing a conceptual framework of experiencing HIV and AIDS information for serodiscordant couples. Second, chapter 8 will act as a transition into the discussion chapter.

Chapter 8

A conceptual framework of information experience

8.1 Introduction

The main aim of the present study was to describe how serodiscordant couples experience HIV and AIDS information. In this present chapter I will revisit and synthesise findings presented in chapters 5, 6 and 7 and identify the key dimensions of experiencing information. While chapter 5 presents the experience of the life-world, this chapter focuses on the experiencing of HIV and AIDS information in the life-world. In addition, the discussion in this present chapter aims to develop a conceptual framework of experiencing HIV and AIDS information and it is divided into two parts. The first part discusses and synthesises the life-world of serodiscordant couples, and the second part describes the nature of experience of HIV and AIDS information.

8.2 The life-world of serodiscordant couples

The life-world is the overarching framework for experiencing HIV and AIDS information for serodiscordant couples. In this section the four existentials of the life-world as proposed by Max Van Manen will be presented as they manifested in the life-world of serodiscordant couples. In addition, the fifth life-world existential, spirituality, identified in this study will be discussed. The aim of this discussion is to develop a visual representation of my conceptualisation of the life-world of serodiscordant couples.

8.2.1 Experiencing HIV and AIDS information through the lived body

The first life-world existential presented in Chapter 5, the lived body, was the pivot of experiencing HIV and AIDS information. As stated by Van Manen (1997) all human beings inhabit lived spaces in bodily form. Therefore, the two partners in serodiscordant relationships were in the world in bodily form. In addition, all people the two partners interacted with were also in the world in bodily form. The serodiscordant couples' consciousness of HIV and AIDS information and its facets was through the medium of the lived body (Bullington, 2013). Serodiscordant couples inhabited lived spaces and interacted with lived others through their bodies, all which had informational value. When the female partner in couple #19 described to me how she developed opinion about HIV and AIDS through casual talk with peers in her community, she was there in bodily form.

All partners in serodiscordant couples interviewed in this study described their lives before the HIV infection. In retrospect they described their bodies without HIV. Being in a stable marriage relationship serodiscordant couples took their bodies and their health for granted. In addition, it is evident that before diagnosis the two partners took their healthy bodies for granted. Namuleme (2013) observes that some HIV and AIDS information labels HIV as a disease of specific groups of people. In the context of my study, before their diagnosis, serodiscordant couples felt they would not be categorised as people susceptible to HIV infection by virtue of being in stable marriage relationships.

Carel (2011) states that as long as there is nothing wrong with the lived body we do not stop to consider the processes going on in it, it remains in the background. Results of the present study suggest that before diagnosis serodiscordant couples found no connection between the substance of HIV and AIDS information and their healthy bodies. During the interview conversations a male HIV positive partner described to me how he used to ignore HIV and AIDS information before his diagnosis. He explained that at that time he considered the issues addressed by HIV and AIDS information not relevant to his circumstances. This attitude suggests that he had a low HIV risk perception. Prata, Elizio, Mark, Morris, and Vahidnia (2006) argue that people who wrongly assess their HIV risk are less likely to act on HIV and AIDS information. Prata et al. recommend that HIV and AIDS information should be designed to assist people correctly assess their risk to HIV infection.

In the present study, incorrect risk assessment resulted in serodiscordant couples being indifferent towards HIV and AIDS information. However, after the HIV diagnosis they became conscious of the HIV infected body for HIV positive partners and the vulnerable body for the HIV negative partners. The fact that the two partners had different HIV statuses was a trigger for information seeking. This is consistent with the findings of the study of young people diagnosed with cancer in Sweden. Snöbohm, Friedrichsen, and Heiwe (2010) reported that young people took their bodies for granted before being diagnosed with cancer. After diagnosis Snöbohm et al. note that even small changes on the lived body such as change in hair quality were cause for concern. The way serodiscordant couples in my study described their bodies suggests that they considered themselves as being abnormal. HIV positive partners described themselves as abnormal because of the virus in their body system. On the other hand, most HIV negative partners did not believe their HIV test results or believed the virus had not reached detectable levels. These views about their bodies caused couples to remark that they feel in their bodies like abnormal people. Such remarks suggest that they considered their bodies as abnormal.

Serodiscordant couples were not satisfied with information provided by people who were not themselves HIV positive. Most couples argued that people who have experienced HIV are best placed to provide accurate HIV and AIDS information. Consistent with this finding some studies have found that people living with HIV consider others living with HIV as important sources of HIV and AIDS information (Namuleme, 2013; Veinot, 2009a). People living with HIV who were involved in activism to inform others about HIV and AIDS used their personal health information (Veinot, 2009a). This information was valued and trusted because it was based on first-hand experience of HIV (Namuleme, 2013).

HIV and AIDS information was experienced through the biological systems of the body. As the lived body, inhabited by HIV, was undergoing physical decline, HIV and AIDS information acted as a lens through which to get insight into the activities of the virus. The current study found that HIV and AIDS information assisted serodiscordant couples to learn about their vulnerability to opportunistic infections. In addition, some couples used HIV and AIDS information on CD4 count to interpret their personal health information. A female partner in couple #10 demonstrated this when she said; *"Women with HIV like me are at risk of developing [cervical] cancer, yes, [cervical] cancer can develop quickly because we have HIV".*

The lived body was an important source of HIV and AIDS information for serodiscordant couples. In Chapter 5 (section 5.2) the lived body was identified as a source of information for the HIV negative partner. At the ART and VCT clinics HIV negative partners were advised to look for certain signs on their spouse's body to assess the risk of HIV transmission. Instances where the said signs manifested the HIV negative partner, without talking to their spouse, would be informed about the risk of HIV transmission. The signs mentioned during interview conversations were lesions or sores. On the other hand, serodiscordant couples who did advocacy work to encourage those they suspected of being HIV positive to go for testing used signs on people's bodies as grounds for their suspicion. In this case experiencing of the HIV infection was regarded as an authentic means of building knowledge about HIV and AIDS. Pointing back at their bodies these couples used their own bodies as examples of successful management of HIV infection.

The findings of this present study indicate that the lived body either concealed or revealed the HIV infection. Serodiscordant couples often mentioned CD4 count as a true measure of the viral load and not appearance of the body. An example given by HIV positive female partner in couple #3 indicates that the lived body also revealed or concealed the HIV infection. She said: *"When you go to the health centres you are told that; 'we can't give you [nutritional flour] because you look health', they don't know that it's the CD4 count that explains the health status of one's body".*

This suggests that one needs some insights into the 'the language' of the lived body in order to discern the HIV and AIDS information it provides. Serodiscordant couples in my study described how, before diagnosis, they failed to understand the signs and symptoms of HIV infection which manifested on the lived body of the HIV positive partner. One male partner said "*she had, what do you call that [**Wife**: candidiasis] yes, she had that, she also had diarrhoea and high fever*" (HIV- Male partner, Couple #17). After diagnosis and living with HIV for some time, some serodiscordant couples became 'experts' in understanding the language of the lived body with respect to HIV infection. This skill is also used on other people as remarked by HIV negative partner in couple #11: "*you see a person with rashes; oh! How can I reach out to this person, then you figure out ways of reach out to that person*".

The bodies of other people (lived others) inhabiting the same lived spaces as the serodiscordant couples were also sources of HIV and AIDS information. Couple #11 described to me how they identified suspected cases of HIV infection and encouraged them to go for VCT. They showed me an HIV and AIDS book titled *How's your health: to help others and yourself feel well*. They said the book described clearly the signs of HIV infection. They told me that using what they read in the book they were able to identify possible cases of HIV infection. The idea that signs on a person's body is an indication of a possible HIV infection supports the notion of the lived body as a source of HIV and AIDS information.

Not many studies have identified the lived body as a source of information. Three studies identified here corroborate my findings. Lloyd (2009) identified the use of the body as a source of information in her study of ambulance officers in Australia. In this study Lloyd reported that ambulance officers look for signs of agitation in the people at the site they are called to. In addition Lloyd reports that ambulance officers also use the patient's body as a source of information. These include seeing the patient is breathing, feeling the pulse rate, and blood pressure. In another study Lloyd (2014) found that when performing their work fire fighters use their colleagues' bodies as a source of information. Lloyd reported that fire fighters observe their peer's bodies in order to make sense of the environment they are working in. Another study by Godbold (2013) observed that people living with chronic kidney disease were able to learn to 'see' into their bodies through measurements such as blood test results. This used an example of a woman who learned how to properly insert a needle into her veins based on sensations she experienced. Similarly serodiscordant couples in my study assessed the authenticity of HIV and AIDS information based on the benefits it brought on their health. As presented in Chapter 6 (section 6.3) serodiscordant couples, despite being religious, chose to disregard HIV and AIDS

information provided by the church and follow that which was provided by the hospital after assessing the health benefits realised.

8.2.2 Lived time, and information experience of serodiscordant couples

As stated by Schutz and Luckmann (1973) "every experience carries a horizon of the past and a horizon of the future". Therefore serodiscordant couples described their bodies in the past with reference to the future horizon. In Malawi HIV is given many names that are descriptive of its effects on the lifespan. Some common names are *mdulamoyo* (life truncating), *mtengano* (we die together) and *mliri* (plague) (United Nations Children's Fund, World Health Organization, and Malawi Government, 2001). This contributed to the HIV positive partners' view of their body as a dying body. HIV infection leads to consciousness of a new self by partners in a serodiscordant relationship. As reported in Chapter 5 and 7 serodiscordant couples described their lived bodies in the past before HIV infection and the present lived body which was a host to HIV and dying. In describing their bodies they made reference to the risk assessment they used to make based on HIV and AIDS information they had accessed. The fact that HIV and AIDS information appeared to label HIV as an illness for the promiscuous was interpreted as excluding them who were in stable marriages. As discussed in the literature review, Anglewicz et al. (2010) in a study of couples' risk perception in Malawi reported that couples had an incorrect assessment of their HIV risk. Interview narratives in my study indicate that at the point of diagnosis serodiscordant couples viewed their lived time as being truncated. Further, couples that had lived with HIV for some time appeared to have reconstructed their lived time and viewed the lived body as a normal one.

All human beings have sub-consciousness of a linear temporal landscape which comprises of the past, present and future (Van Manen, 1997). In the present study serodiscordant couples reported that HIV infection truncated their life span. As a result, they were worried if they would live long enough to bring up their children. At the HIV testing centres HIV negative partners were told that their HIV status could just be as a result of the virus hiding in their bodies, eluding HIV testing. As such, most HIV negative partners spent their lived time waiting for information about their HIV status.

Serodiscordant couples noted that most HIV and AIDS information available to them did not adequately address serodiscordance. This created a sense of uncertainty about the future. Even where HIV and AIDS information was available it did not necessarily result in reduction of uncertainty. It all depended on the type of HIV and AIDS information. For instance, HIV and AIDS information that warned people about the risks of unprotected sex increased uncertainty in the

HIV negative partner, and information that warned people about the deadly nature HIV created uncertainty in both partners.

Some of the issues emerging from this finding relate specifically to the artificial way of living created by the HIV and AIDS infection. The new ways of living prescribed in HIV and AIDS information as means for coping with the HIV infection were viewed by serodiscordant couples as burdensome. This resulted in serodiscordant couples experiencing a tortuous passage of lived time owing to the routines introduced because of the HIV infection. This is exemplified in the description of the female partner in couple #11 of her experience of ART. She said; *"Some of these messages, for me it is something that distresses my heart. A life of taking medicine every day is so painful"*.

Kuhlthau (1993)'s process of information searching suggests that success in the search process results in satisfaction and reduction of uncertainty.   However, other insights into information seeking and illness-related uncertainty suggest otherwise. Brashers (2006) argues that the amount of information one has is not related to the levels of uncertainty. Brashers states that one can have access to all information there is but still experience uncertainty. Further, he states that people can experience uncertainty because of contradictory information. Brashers' view is consistent with the findings of my study where some serodiscordant couples experienced increased levels of uncertainty after accessing HIV and AIDS information.

 Results from the current study indicate that some couples were able to transcend their illness and develop a new sense of lived time. As indicated in chapter 5 (section 5.2) serodiscordant couples who had lived with HIV for some time and had transcended their illness were sources of HIV and AIDS information for others. These couples were able to compare their physical decline before ART and their situation at the time of the interview. This made them to feel good about themselves and their situation. Marks, Murray, Evans, and Estacio (2011) state that coping with HIV and AIDS is multidimensional, influenced by personal, contextual and cultural factors. Marks et al. posit that skills essential to coping with HIV and AIDS include information seeking, relaxation exercises, cognitive reframing and problem solving among others.

Some serodiscordant couples used their religion to reconstruct their lived time. Evidence from the interviews suggests that some serodiscordant couples accepted that their lived time was truncated, but they were looking forward to another lived time after death. One couple told me that they believed that in heaven there is a cure for HIV.

As mentioned in section 5.4 most serodiscordant couples who had children described their lived time in relation to their ability to live long enough to bring up the children. This experience of lived time manifested itself in three ways. First, serodiscordant couples appeared to experience lived time as extending from past to present into the future. Most serodiscordant couples felt that HIV infection truncated the linear lived time. Secondly, serodiscordant couples who viewed their linear flow of lived time as truncated were anxious about their longevity and ability to look after their children. With respect to children, they were concerned about transmission of the virus to their babies and truncating the babies' lived time. This experiencing of lived time triggered the need for information on how to manage the HIV infection in order to live a long life. Serodiscordant couples also needed HIV and AIDS information on prevention of transmission from mother to child. Thirdly, serodiscordant couples who had accepted their illness and reconstructed their lived time referred to children they raised as evidence of the possibility of them living a long life, despite the HIV infection.

These results are in agreement with Zhou's (2010) findings which showed that people living with HIV have three conceptions of lived time. The study of people living with HIV in China found that they experienced linear flow of lived time or time with respect to their relationship to others. In addition, Zhou found that people living with HIV have reconstructed lived time based of reorientation of life priorities. In my study, serodiscordant couples described how HIV and AIDS information facilitated the reconstruction of lived time. Couples' descriptions suggest that HIV and AIDS information provided tips on how the 'truncated' life span could be reconstructed through "*good diet, good and comfortable sleep, looking after your body, and finding time to do different exercises*" (HIV+ Male partner, Couple #6 separated).

8.2.3   Lived spaces where serodiscordant couples experienced HIV and AIDS information

As indicated in Chapter 5 serodiscordant couples inhabited different lived spaces. All couples interviewed in this study had a home which was a shared space for the couple and their children. The findings of my study suggest that most couples had access to HIV and AIDS information through radio and television in their homes. However, before diagnosis this information was considered to be relevant to people that were not married, and sex workers. For most couples, the diagnosis was the turnaround of life events. Couple #17 described it as the time HIV became real. It appears that from that point information from the radio and television was experienced differently. In addition, couples started seeking information from outside the home. Chatman (1999) argues that as long as everything is working well in their small world, people will not seek

information from outside. Besides, for married couples the home is a private space (Bollnow, 1961) and most of dealings between the two partners do not require counsel from outside.

The findings of my study suggest that HIV and AIDS information was experienced with a sense of betrayal. Since HIV and AIDS information highlighted unprotected sex as one of the major means through which HIV is transmitted, it entailed that the private space, the home, had been invaded by a third person. For the HIV negative partner this information was experienced as a pronouncement of their unfaithful behaviour. On the other hand, HIV and AIDS information provided by professional counsellors at ART and VCT clinics, and some religious leaders was reassuring. My findings suggest that this information was used to re-establish the integrity of the home as a private lived space.

As presented in chapter 5, the HIV infection changed the experience of home as a lived space. HIV introduced certain routines in the lives of serodiscordant couples. Therefore objects such as wall clocks were linked to information leaflets in medication bottles as symbols of routineness of the couples' lived time. In the privacy of their homes couples were able to adhere to these routines while maintaining the confidentiality of their HIV status. As presented in chapter 5, the home provided a safe place to keep HIV and AIDS information.

Traditionally, in Malawi, the home has spaces that are shared with the children and a private bedroom for parents. Children are advised not to enter their parents' bedroom (Munthali and Zulu, 2007). This indicates that, though shared, the home is a private and safe space for married couples. Evidence presented in Chapter 6 (section 6.10) indicates that before diagnosis serodiscordant couples believed that HIV only infected people that were not married and were sex workers. As a result, serodiscordant couples believed they could not be infected with HIV within the home. Therefore, condom use in the home was considered unnatural. Chimbiri (2007) notes that because the marriage relationship is considered exclusive to the two partners, introducing condoms is often considered as communicating a contrary message.

The home was a familiar space occupied by the serodiscordant couples. However, after diagnosis In the present study most male partners, regardless of their HIV status, objected to the use of condoms with their spouses. The reasons for objection were based on information obtained from informal personal sources of HIV and AIDS information. On the other hand, some female partners agreed not to use condoms because of their desire to have children. Other couples were discouraged by their religions where it was argued that sex in marriage is God's plan and it was not necessary to use condoms. These findings confirm Chimbiri's (2007) findings where couples were found to believe that marriage was invented by God and it has some special

characteristics that makes a condom to be an intruder. When results of this present study are taken together with those of Chimbiri (2007) we can conclude that HIV and AIDS information on condoms was viewed by serodiscordant couples as for people who are not married.

Results of my study indicate that the safety of the home as a lived space was threatened by the HIV infection. This was demonstrated by blaming of the HIV positive partner with statements such as *"where did you get this thing"*. A study on coping strategies of serodiscordant couples in Kenya found that the initial reaction to discordant results for 94% of participants was to blame the HIV positive partner of infidelity (Gitonga, Ballidawa, and Ndege, 2012). A possible explanation for this accusation is that HIV and AIDS information highlights unprotected sex as the major driver of the HIV pandemic. As presented in the results chapters some male HIV negative partners chased their spouses from their homes after diagnosis. As discussed in section 8.2 and in the results chapters (5, 6 and 7) HIV negative partners in this present study perceived themselves as not being susceptible to HIV infection.

Another important finding of this study was the labelling of HIV negative people as 'spies' in HIV and AIDS support groups. As defined by the Oxford English Dictionary a spy is a person who secretly collects or obtains information on an enemy (Oxford University Press, 2000). This implies that HIV negative partners went to HIV and AIDS support groups with bad intentions. The rejection of HIV negative partners who were in serodiscordant relationships in HIV and AIDS support groups appears to be omitted in literature. Since HIV and AIDS support groups are set up to support people living with HIV, positive serostatus is a default criterion for membership. HIV and AIDS support groups as lived spaces are designed to be safe and supportive to people living with HIV as they are marginalised and stigmatised in their homes and society (Ramlagan et al., 2010). In their study of HIV and AIDS support groups of women living with HIV in South Africa Ramlagan et al. observed that HIV and AIDS support groups provided an opportunity for the women to escape stigma and discrimination to discuss issues affecting them in the company of others experiencing the same problem. While this is supported by research evidence, it only holds for people living with HIV who are in seroconcordant relationships. Evidence from this present study suggests that HIV positive partners in some serodiscordant couples stigmatised and discriminated their HIV positive spouses. There is also evidence suggesting that HIV negative partners needed support to cope with the HIV infection of their spouse. They needed support to come to terms with the HIV infection of their spouse, prevent themselves from being infected, and manage the relationship with their spouses.

Lived spaces were instrumental to the experiencing of HIV and AIDS information for serodiscordant couples. Findings of the present study suggest that some lived spaces were supportive while others were neglectful. A good example illustrating this is experience of an HIV negative partner at the HIV and AIDS support group attended by his wife. Being HIV negative, he was considered a 'spy' among the HIV positive people. This is consistent with Chatman's (1999) concept of social types. She argues that social typing introduces a classification scheme by which individuals are judged as either insiders or outsiders in a small world. This suggests that the further a person is removed from the group's typology the more difficult they are to share information with.

In Figure 8.1 I represent the lived spaces inhabited by serodiscordant couples.
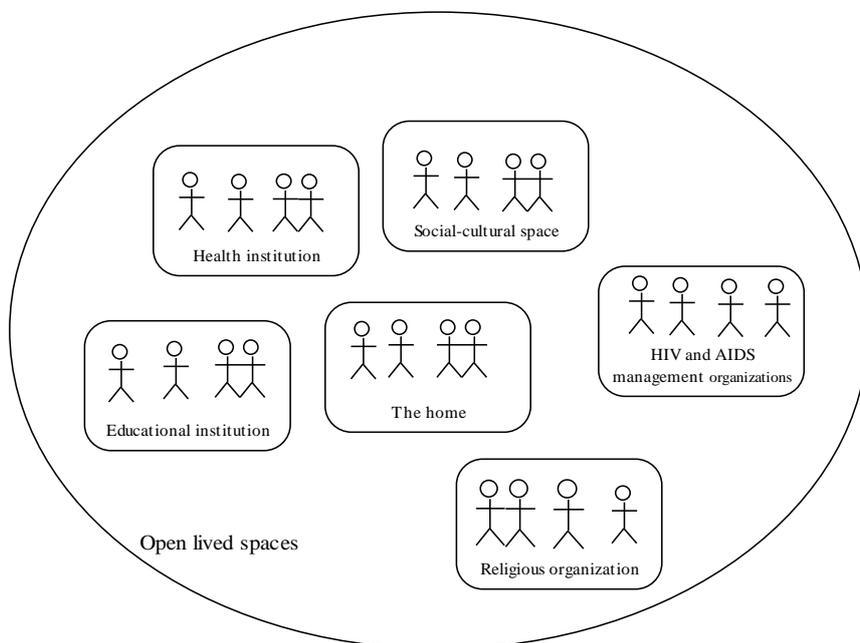
Figure 8.1: Lived spaces for serodiscordant couples

In the representation in Figure 8.1 I posit that the lived spaces comprise of many small worlds. For instance a health institution such as a hospital will have small worlds such as ART clinic, VCT clinic, HIV and AIDS research centre. Phenomenologically, the experience of space in all these small worlds is that of the hospital. This was evidenced by serodiscordant couples' failure to distinguish between doctors, nurses, VCT counsellors and ART staff. In addition, everything in this environment was called hospital. As stated by Van Manen (1997, p. 102) "lived space … is felt space" so all these spaces felt like the hospital. On the other hand, some of the lived spaces represented in Figure 8.1 are themselves small worlds. A good example is the home. For all serodiscordant couples the home was experienced as a safe and welcoming space which was

194

made unsafe and neglectful by the HIV infection. As a small world the home is a social environment where family members live bound by physical structures, and cultural norms (Burnett et al., 2008).

8.2.4   Experiencing HIV and AIDS information with lived others

As shown in figure 8.1 serodiscordant couples occupied most lived spaces with other people. Other people's opinions and interpretations contributed to meanings serodiscordant couples derived from HIV and AIDS information. Evidence from interview conversations suggests that lived others had both positive and negative influences on couples. This finding is supported by Coma (2014) who found that attitudes of couples, and likely sexual behaviour are largely influenced my opinions and expectations of peers. Most couples in my study had children who were reliant on the care of the two partners. This affected the experiencing of HIV and AIDS information. For a single mother I interviewed (couple #10 separated), children were a motivation for her to act on HIV and AIDS information. She remarked: "*Fear comes from realisation that if I sleep with many men they will kill me; they will give me the viruses they have in their bodies …and I have children, I will leave my children" (HIV+ Female partner, Couple #10 separated)*". This comment suggests that HIV and AIDS information was viewed as assisting in achieving long life for the sake of the children.

In Malawi traditional marriage formalities include ceremonies where important information, including HIV and AIDS information, is relayed to the bride and groom (Gombachika et al., 2013). The present study found that the two partners' kin had influence on reproductive decisions, including the management of the HIV infection. Clear examples of influence of relatives are in couple #6 and couple #19's stories. The male partner in couple #6's said that he was aware of relatives' desire for the couple to bear children. Awareness of such desires influenced couples to ignore information that encouraged consistent condom use.

As discussed in section 8.2.3 serodiscordant couples experienced HIV and AIDS information in lived places such as the ART and VCT clinics, hospitals and HIV and AIDS support groups. In these places serodiscordant couples interacted with other people inhabiting the same lived spaces. Firstly, they interacted with other serodiscordant couples or other people living with HIV. Secondly, these lived spaces were inhabited by staff working for institutions that managed the services.

As depicted in the Figure 8.1 other people occupied the same lived spaces as the serodiscordant couples. These were also experiencing HIV and AIDS information. Some *lived others* who were poorly informed about HIV and AIDS were sources of wrong information for serodiscordant

couples. Evidence from interview conversations suggests that the communities in which serodiscordant couples lived had socially constructed views about HIV and AIDS. Some serodiscordant couples said that their *"church teaches that, it is sin to use condoms"* (HIV+ Male partner, Couple #1). Another couple that went to a traditional doctor was told that the illness was the work of ancestral spirits that wanted to give the infected person prophetic powers. It is also evident from interview conversations that these socially constructed views about HIV and AIDS affected the management of the HIV infection among serodiscordant couples. This is consistent with the sociologists' view of illness. White (2002) criticizes the medical model of disease and illness which espouses that it is a physical thing where germ or virus or bacteria enters the body and causes it to malfunction. White contends that disease and illness is much of a social process as it is a biological process. Similarly, Rugalema (2004) argues that there is little or no blending between the scientific perception of the HIV pandemic and the socially constructed views. As a result the scientific perceptions and interventions are pushed on local people with no or little interventions.

8.2.5   Spirituality: belief in God and ancestral spirits

One dominant theme in this study was religion and belief in ancestral spirits. All serodiscordant couples in this present study were either Christians or Muslims. Couple #17 indicated during the interviews that religion was a source of their strength in a life that was devastated by the HIV infection. However, the same couple had encountered some religious leaders who blamed them and claimed that it was because of their sins that one partner had HIV. The blame was described as painful because religion was considered important in the management of the HIV infection for serodiscordant couples. In addition, in the absence of "*concrete solutions*" (HIV+ Male partner, Couple #11) to the pandemic in HIV and AIDS information, some serodiscordant couples indicated that they found hope in the reading of the sacred books of their religions.

As described in section 8.2.3 serodiscordant couples practiced their religious beliefs by among other things inhabiting lived spaces. These spaces were places of hope. Couples believed that through prayer they were able to speak to God and get answers to questions the medical world was not able to provide. For instance, one HIV negative partner told me that through prayer, God came and took away her anxiety.

Religious meetings were also social gatherings which included sharing of personal testimonies. In addition, some religious leaders were themselves living with HIV. Some serodiscordant couples also claimed to have had testimonies of activities of ancestral spirits. Couples #20 justified their decision to go to a traditional doctor with previous experience of similar illness of the HIV positive

partner's relative. These characteristics of religion and ancestral spirits made information provided believable. However, my study found that most serodiscordant couples also believed that not everyone can be healed by prayer. They believed healing through prayer is by God's will. Although some couples maintained that they still believed traditional doctors can heal some diseases, most couples reported to have realised that traditional doctors could not heal their HIV infection and decided to go to the hospital.

Although all serodiscordant couples were either Christians or Muslims, evidence from interview conversations suggest that most couples also subscribed to traditional belief systems. As presented in chapter 5 (section 5.5.1) examples include consultation with traditional doctors and belief in ancestral spirits.

Spirituality was also important in the experiencing of HIV and AIDS information in the context of lived time. HIV and AIDS information was described as not inspiring hope for the future. Describing her experiences Carel (2013) observes that terminal illness causes patients to discount the future and concentrate on living in the present. True to Carel's observation, serodiscordant couples in my study appeared to have discounted the future in the linear dimension of lived time. However, most couples believed they would live again in heaven and that their religious books had promises of an HIV free life there. This finding identifies the importance and complementary roles of the different sources of HIV and AIDS information for serodiscordant couples.

Van Manen (1997, p. 105) posits that human beings search in lived others for "a sense of purpose in life, meaningfulness, grounds for living, as in the religious experience of the absolute Other, God". This remark appears to suggest that God is different from lived others. In addition, the elusive nature of the ancestral spirits also suggests that they are also different from lived others.

Home, cultural institutions, religious institutions, health facilities, support groups

Linear, relational and reconstructed

Lived time

Lived space

Lived others

Lived body

Spouses, family, nurses, counsellors, peers

Spirituality

Religion, belief, faith, taboos

Health, emotions, relations
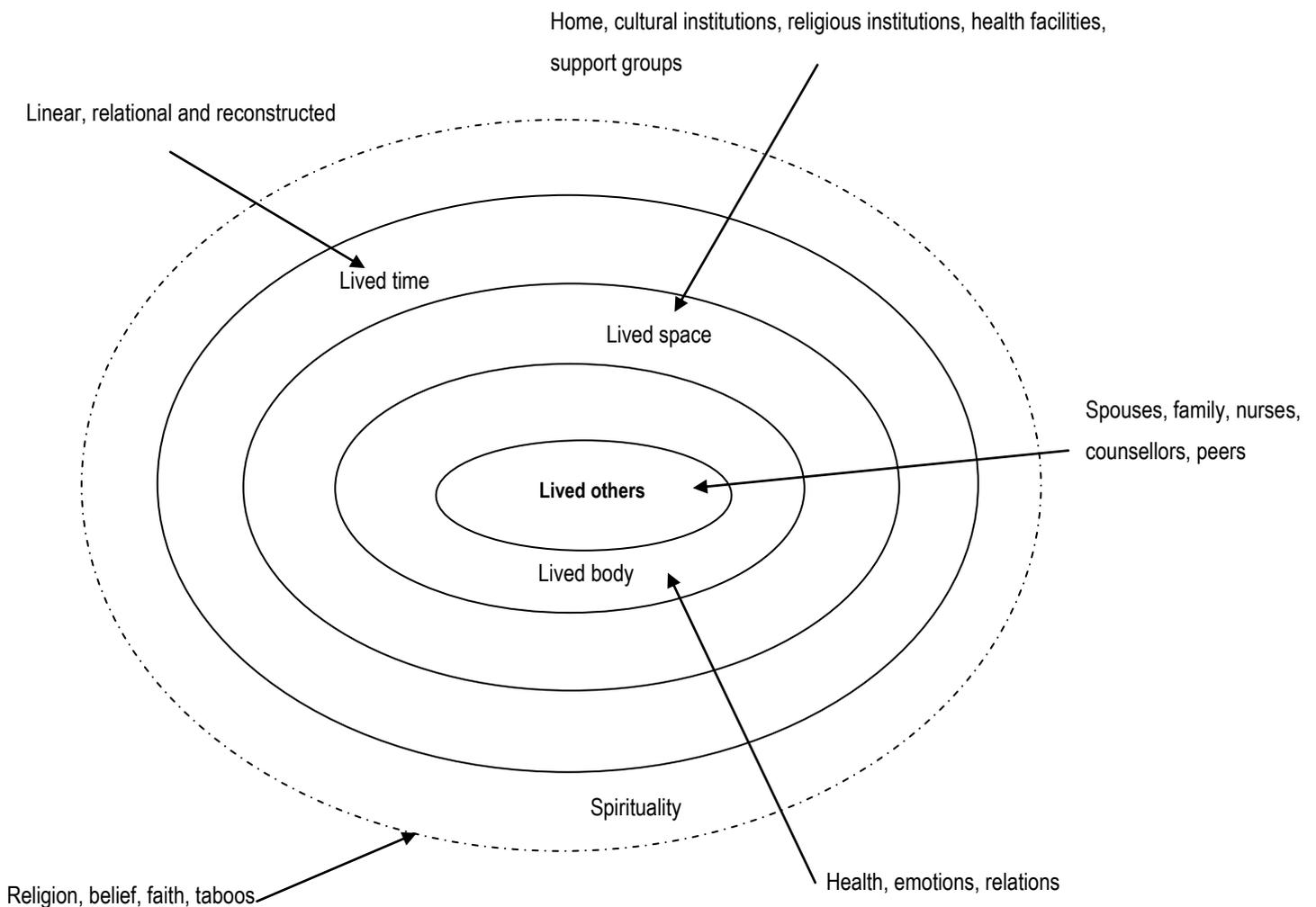
Figure 8.2: The life-world of serodiscordant couples

As depicted in figure 8.2, the core of a life-world is the lived body. At the centre of the diagram are lived others, indicating that these exist in the world in bodily form. The third circle in the diagram represents lived spaces. This suggests that all people inhabit lived spaces as lived bodies. Next is the temporal dimension in which all people play out their lives. As described in chapter 5, this is subjective rather than clock time. The fifth existential represented with a dotted line in figure 8.2 is spirituality.

8.3   Information experience

Information experience is defined as people's multidimensional engagement with information in their life-world (C. Bruce, Davis, Hughes, Partridge, and Stoodley, 2014). Tucker (2014) observes that while information behaviour research focuses on skills, techniques, and participant's traits, information experience research is integrative focusing on cognitive, affective and interpersonal elements. In addition, information experience is concerned with the interrelation between people

and their life-world, and views people and their everyday world as inseparable (Yates, Partridge, and Bruce, 2012).

When I interviewed couple #11 the male HIV positive partner described what phenomenologically would be considered a dialogue with HIV and AIDS information. HIV and AIDS information described HIV as a killer and all people infected with the virus will die. He said: "*I will die, I will die, yes I will die. But like I said in our support group we have pastors who are also HIV positive and they I always tell us that; 'friends let's look at all people who have died this week, were they all HIV positive*'". This excerpt suggests that HIV and AIDS information created an internal monologue which constantly reminded him of the imminent death. This example of information experience suggests that it an internal process much as it is external. Probably the male partner in couple #19 demonstrates this more precisely. Although he was HIV negative, he reflected on HIV and AIDS information, and his behaviour. He was convinced he was HIV positive, and he had infected his wife. He said:

> "*in my mind I had many thoughts; that they say HIV infection is through promiscuity, sleeping around with women or men. So I was confused; where did I get this AIDS, because this is not my first wife, my first wife was from Lilongwe, we broke up here and sent her back to her home, this one is my second wife. So when she was found positive I was surprised and asked myself; 'could it be that [first] woman infected me*'".

The preceding interview excerpts suggest that we cannot grasp information experience as it occurs. Information experience as any other lived experience can be described reflectively as a past occurrence (Van Manen, 1997).

8.3.1   What is HIV and AIDS information experience like?

As presented in chapter 7 (section 7.2), serodiscordant couples experienced HIV and AIDS information sources before experiencing the information itself. The sources of HIV and AIDS information that were experienced by serodiscordant couples were within their life-world, some which were the structures of the life-world itself. There were some sources which were outside the life-world. However, all information experience was within the life-world.

Before proceeding I wish to distinguish between the two concepts: information and information source. Maguire, Kazlauskas, and Weir (1994) defines information source as a location or container in which information is kept. An information source can be an object, a place, a person, or an organisation. I will now revisit the definition of information with the aim of describing the relationship with information source. In chapter 2, different definitions of information were

discussed, signifying the problematic nature of defining the concept. A detailed discussion of what constituted HIV and AIDS information for serodiscordant couples in my study will be done in chapter 9. At this stage it will suffice to say that information is that which is communicated to aid knowing or to impart meaning.

In the context of the present study, determining hard and fast boundaries between information and information source appeared to be problematic for some HIV and AIDS information sources. A good example is the lived body which is identified as a source of HIV and AIDS information in chapter 6 and in Lloyd's (2014) study of ambulance officers (cited in section 8.2.1). In addition to being a source, serodiscordant couples in my study described the appearance of the lived body of an HIV positive person as HIV and AIDS information. Another example is music. While music is identified as a source of HIV and AIDS information, when a song is playing then it becomes HIV and AIDS information.

Serodiscordant couples inhabited various lived spaces some which were information sources. They were in these lived spaces in bodily form and interacted with others in bodily form. Some of the lived others inhabiting the same lived spaces as serodiscordant couples were also sources of HIV and AIDS information. In their life-world, the experience of HIV and AIDS information for serodiscordant couples was through the actual living through events and not in their imagination. It was through living their lives.

Webster (1959) defines experience as the actual living through an event …real life as contrasted with the ideal. In addition Erlich (2003) contends that experience is usually accompanied by some affective signifiers. However, some people, through disassociation, repression or ego weakness, cannot register these affective signifiers of experience. This is consistent with the results of the present study which indicated that some partners in serodiscordant relationships experienced HIV and AIDS information with emotions that could be described as ambiguous.

Findings of my study suggest that HIV and AIDS information was experienced in four stages. First, serodiscordant couples experienced HIV and AIDS information while anticipating the information. Secondly, information was experienced while interacting with it. Interaction with HIV and AIDS information was through physically holding information materials, browsing through, and reading. In addition, it also involved listening radio or watching television and cognitively processing the information. Thirdly, serodiscordant couples experienced HIV and AIDS information while acting on it. Lastly, while anticipating, interacting with and acting on HIV and AIDS information, serodiscordant couples continually experienced it by reflecting on it. Thus, the fourth stage of experiencing HIV and AIDS information was 'reflection' which occurred in all the

three stages described. These findings are in part consistent with what Heinström (2014) described. According to Heinström, "information experience may occur in anticipation of an information interaction, during it, or as a consequence of it" (p.276). As shown in Figure 8.3, some of the sources of HIV and AIDS information were inside the life-world and some outside the life-world. I will first introduce two concepts; evaluation and filtering that are important to experiencing HIV and AIDS information in sections 8.3.2 and 8.3.3. In sections 8.3.4. to 8.3.7 I will introduce the concepts of anticipating information, interacting with information, acting on information, and reflecting on information. When discussing these concepts I will draw on the themes from my analysis.
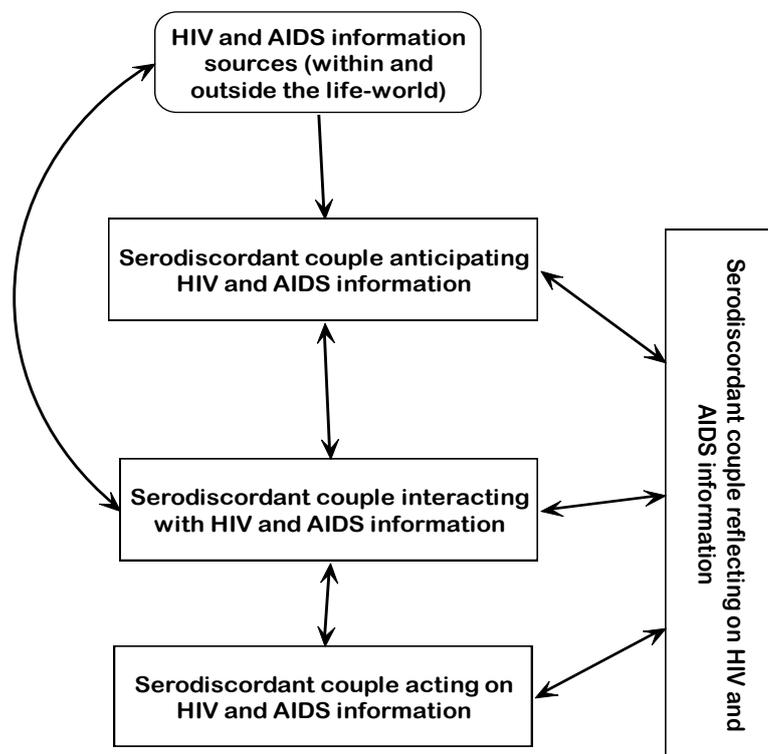
Figure 8.3: Stages of experiencing HIV and AIDS information

Figure 8.3 delineates the stages of experiencing HIV and AIDS information. HIV and AIDS information that was experienced by serodiscordant couples either came from within the couples' life-world or from sources outside of it. HIV and AIDS information was experienced at four stages. The first stage is where HIV and AIDS information was experienced while anticipating it. The second stage is where HIV and AIDS information was experienced while interacting with it. Information was also interacted with while acting on it. Finally, HIV and AIDS information was experienced while reflecting on it. I will now discuss these stages in detail.

First, HIV and AIDS information is experienced during the time it is being anticipated. Some HIV negative partners described experience of fear and anxiety while anticipating personal health information about their HIV status. The following narrative from an HIV negative partner demonstrates that experience. He said: "*That gave me fear. I started thinking that what if she is found positive, what am I going to do? How am I going to handle that situation? Will she stay alive? Or she will die*" (HIV- Male partner, Couple #17).

The second step in Figure 8.3 is interacting with HIV and AIDS information. Interaction here has a connotation of a dynamic relationship between people (the individuals in a serodiscordant couple) with HIV and AIDS information (Fidel, 2012). As indicated in Figure 8.3 some information can be interacted with without anticipating it. The third stage of experiencing HIV and AIDS information is acting on the information. The bi-directional arrow between the *interaction* and *anticipation* stages aims to address cases where HIV and AIDS information was provided in steps. Between those stages couples continued to interact with information while anticipating more of it. A common example is VCT sessions where couples were first told that the illness of one partner requires HIV testing. This was followed by process of obtaining consent, a counselling session, testing, and the results. Similarly, the bi-directional arrow between *interaction* stage and *acting* stage suggests that in some circumstances serodiscordant couples continued interacting with HIV and AIDS information while acting on it. A good example is when serodiscordant couples used a process outlined in a book to resolve a health problem.

The fourth stage of experiencing HIV and AIDS information was reflection. Reflection is "the process of internally examining and exploring an issue of concern, triggered by an experience, which creates and clarifies meaning in terms of self, and which results in a changed conceptual perspective" (Boyd and Fales, 1983, p. 100). As depicted in Figure 8.3, reflection on HIV and AIDS information occurred at all other three levels discussed. Serodiscordant couples continually reflected on HIV and AIDS information while anticipating it, interacting with it, and while acting on it. In the sections that follow I discuss **evaluation** and **filtering** of HIV and AIDS information, and then discuss the stages of experiencing information in greater detail.

8.3.2   Evaluation of HIV and AIDS information

Evaluation was an important aspect of experiencing HIV and AIDS information for serodiscordant couples. Bloom, Englehart, Furst, Hill, and Krathwohl (1956, p. 185) define evaluation as "the making of judgments about the value, for some purpose, of ideas, works, solutions, methods, material ... It involves the use of criteria as well as standards for appraising the extent to which particulars are accurate, effective, economical, or satisfying". The first form of evaluation was

when one partner encounters or finds unfamiliar HIV and AIDS information they discussed it with their spouse. Although few couples mentioned this form of evaluation, evidence from interview conversations suggests that couples that discussed HIV and AIDS information had positive relationships. Intra-couple communication is identified in previous studies as an attribute of cohesive marital relationships. Particularly, Salazar, Figueroroa, Girón, and Cáceres (2009) identify lack of communication among married couples as a cause for many marital problems.

Other couples assessed the validity of HIV and AIDS information by comparing with information from sources they considered as trusted. The most common trusted source for serodiscordant couples was the hospital. For instance, when I asked couple #1 if there is information they do not use after receiving, the female partner responded: "*yes, there is. Like information that discourages condom use. We follow what we are told at the hospital because of the situation we have in this house*"

In the following quote the HIV positive partner in couple #3 demonstrates how she evaluated some HIV and AIDS information. "*I like trying out, when I am told something, I like trying it out. I have an example; I heard that when you have a wound…because I usually have sores on my genital area, in the book, 'Living in hope' they say you can take garlic, peel it and swallow like tablets*". When this worked she was convinced that the information is trustworthy. This example suggests that HIV and AIDS information was not only evaluated cognitively. It was also evaluated practically by trying it out.

Some serodiscordant couples, despite having HIV and AIDS information from different sources were still not sure of the truth about HIV in general and serodiscordance in particular. Therefore, HIV and AIDS information was evaluated to establish its truthfulness. A male HIV negative partner in couple #17 remarked: "*What I am telling is real, when you hear those song you fear but when you go to the hospital for ART, at the therapy clinic they give you different information. Now you realise that this is different from the rubbish I was told*".

The definitions of reflection and evaluation, taken together with evidence from interview conversations, suggest that evaluation was a form of reflection. Therefore, the process of evaluating HIV and AIDS information is conceived in this study as occurring within the 'reflection' stage of experiencing HIV and AIDS information.

8.3.3   Filtering information

Case (2012) observes that in our daily lives we are confronted with too much information more than we can pay careful attention to. Case further argues that when bombarded with a lot of

information the natural human response is to filter out irrelevant information. Considering that HIV and AIDS information is complex, hard to understand and voluminous (Hogan and Palmer, 2005) selective treatment of that information may not always be a negative thing (Case, 2012). Case contends that filtering of information can be beneficial when there is not enough time and energy to pay careful attention to all of it. An HIV negative male partner in couple #2 remarked: "*When information is broadcast, like on the radio and you are in a bus, your mind is where you are going. You can hear the message, but there are two levels of hearing. There is casual hearing, and hearing with comprehension. Those things we hear but for you to grasp the essence, the mind is where you are going*". Thus, the findings of the present study suggest that HIV and AIDS information can also be filtered where the mind is preoccupied by other things that are considered more important than HIV and AIDS at that particular time. In the context of the present study information filtering includes ignoring, rejecting and delaying interaction with the information.

Results of this present study also suggest that HIV and AIDS information was filtered when it was found to be inaccessible. Three factors were identified as contributing towards inaccessibility of HIV and AIDS information and hence filtering. The first factor was the format in which information was presented. Serodiscordant couples that were illiterate found HIV and AIDS information in print format inaccessible. I observed in Chapter 7 (section 7.3) that some serodiscordant couples had received HIV and AIDS information in print format and in the local language, but because of illiteracy they were not able to use those materials. The second factor was competency in the English language. The results of the present study suggest that serodiscordant couples that were literate but not competent in the English language found English HIV and AIDS information materials inaccessible. A vivid example of this is an HIV negative female partner in couple #7 who was illiterate and said she was not able to use printed HIV and AIDS information. She remarked: "*I prefer information on the radio, because on the radio am able to hear from beginning to the end*". The third factor that contributed towards inaccessibility of HIV and AIDS information was cost. Costs that were mentioned by serodiscordant couples were associated travel to places where information was available, and buying information materials.

HIV and AIDS information was also filtered when it came from sources considered untrustworthy. Trustworthiness in this case was not necessarily to do with the correctness of the information. According to Chatman (1999), in the small-world perspective information is trusted when it comes from a member of that small-world. In addition, Chatman contends that people will only cross the boundary to seek information from outside their life-world if that information is believed to be critical or if life in the small-world is no longer functioning. Although hospitals were mentioned by most serodiscordant couples as trusted source of HIV and AIDS information, one woman told me

that: "*for me when a doctor is not one of us [not HIV positive] they do something that hurts us…when I get information from them I receive it while knowing the information cannot assist me*.

Another issue that necessitated filtering of HIV and AIDS information was the perceived lack of quality. One respondent believed that some HIV and AIDS information is not adequately tried out to ascertain its effectiveness before it is used in information campaigns. "*Sometimes I feel they bring out information with a message touching on sensitive issues before they have thought through it*" (HIV- Male partner, Couple #17). However, Marshall and Williams (2006) contend that the appropriate starting point when investigating how consumers evaluate health information is to determine what constitutes quality for health information. In the United Kingdom there are published health information standards for consumers. These include The Information Standard which certifies organisations that produce health information.

Some serodiscordant couples filtered HIV and AIDS information because of the language which was found to be too explicit and inappropriate. The female HIV positive partner in couple #13 told me that: "*before diagnosis when I hear about HIV and AIDS I took it as something useless, I realised that those messages were important because when I fell ill I went to many hospitals until one hospital suggested that I get tested. When I was found positive it's when I found the evidence that those messages were true*". However, other couples rejected or ignored HIV and AIDS information after diagnosis. A good example is provided by couple #9 who said: "*They are too explicit, the problem is that children will copy and try out what is said, because in our days there were no such things, talking obscene things anyhow, that is indecency*" (HIV- Male partner, Couple #9).

8.3.4   Anticipating information

Phenomenologically, anticipation is the prevision of that which will be experienced (Schutz, 1972). Schultz argues that for every experience we are able to have a foresight that is empty, vague and lacking its proper 'filling-in' (p.58). Through anticipation we interpret situations and it influences our selection of what is relevant from a mass of information we encounter (Hayes, 2009).

When I interviewed couple #18 the husband had just been diagnosed and the wife was waiting for her third HIV re-testing. The hospital told her that she was not cleared yet, and that the virus might just be hiding in her body. She was still anticipating information about her HIV status. The uneasiness that was created by that anticipation was revealed in her constant questioning of the future. In addition, both partners told me that they were not adequately informed about HIV and AIDS. As a result they had unanswered questions about many aspects of their lives. On one hand

the male partner explained that he wanted to know "*how we can stay as husband and wife*" and on the other hand, the female partner wanted to know "*But will my husband and I live a long life to bring up our children, how can we look after our children since my husband has the virus maybe he can die today?*". This questioning of aspects of their lives with respect to serodiscordance indicates the anticipation for their interaction with HIV and AIDS information which will possibly answer these questions. Another good example of experiencing HIV and AIDS information while anticipating it was given by a male partner in couple #6 who had separated from his wife. Although the couple separated, the male partner was anxious to know if they could bear a child. When I asked him to describe the aspects of child bearing he wanted to know, he responded by giving a list of questions that linger on his mind. Some of the questions mentioned were; "*is it possible for us to have children? What problems can I or my wife face if she becomes pregnant?*"

As shown in figure 8.4, information was evaluated for cultural, religious and medical correctness and relevance. Information that was deemed not correct or irrelevant was filtered. There is evidence from interview conversations that some HIV and AIDS information being anticipated was filtered before serodiscordant couples interacted with it. Most cases where HIV and AIDS information was filtered were before diagnosis. Some information, though correct and relevant was also filtered just to delay interaction with it. A good example is when HIV negative partners, whose partners tested alone and found positive refused to go for testing. The findings of my study suggest that male partners were afraid to know their HIV status when their spouses were found HIV positive. This is captured in the following interview excerpt:

> *My major concern is men; it is usually difficult to get a man to go for testing. For women it is easier, whether you like it or not once you are pregnant it is mandatory for you to get tested. Now when the husband finds out that his wife was found positive, that the end of the marriage. After that the husband will re-marry without going for testing (HIV+ Female partner, Couple #17).*

In this example, HIV and AIDS information was filtered to delay interaction with it for emotional reasons. It should be noted that the length of time for anticipating HIV and AIDS information was variable, ranging from long to very short. For instance, when one partner tested HIV negative they were told to go back after a few months for another test to confirm their HIV status, and a couple encountering HIV and AIDS information would have as short a time as a few seconds to anticipate it.

8.3.5 Interacting with information

Information interaction is a reciprocal action that involves a human being and the information object (Marchionini, 2008). Marchionini contends that the action can be mental or physical and effect some changes in the human being and on the information object. In the strictest sense the term 'information interaction' is reserved for situations where the information objects reciprocate the human's actions. In the context of the present study the concept is used loosely to mean serodiscordant couples being consciously aware of the information object and its contents.

In most cases after the anticipation stage serodiscordant couples interacted with the HIV and AIDS information. When interacting with HIV and AIDS information serodiscordant couples experienced it in different ways. One of these experiences was captured in a story of couple #17. Before diagnosis the male partner who was a blood donor had many blood tests that came out negative. In the mind of this couple they believed that the wife's illness could not have been HIV and if it were HIV it would have been transmitted to the husband. "*Now when reading the NAC newsletters we were noticing that the signs being described are exactly what we were seeing on this person".* At this point the two partners looked at each other and continued and he described what the experience was like:

> *"Before I tested the experience was what I described earlier that we began to draw parallels with what was happening to her. We started to realise that the issues being discussed [in this newsletter] are not out of the blue, they are real. That was my first time to come face to face with signs of HIV. At that point I began to realise that AIDS is not far from us. That gave me fear. I started thinking that what if she is found positive, what am I going to do? How am I going to handle that situation? Will she stay alive? Or she will die. I had these questions but I could not disclose my fears. Now when she was found positive, when she called me and told me that; I went for testing and these are the results. I did not want to show how... should I say shocked? No not shock, but I was defeated, saying; Now it has caught me! What should I do to continue loving her, how will I show her that I am not shaken by this, although within me I was shaken"* (HIV- Male partner, Couple #17).

In the above remark the male partner describes the internal dialogue triggered by HIV and AIDS information. The tone of this internal dialogue suggests that HIV and AIDS information was experienced with fear and uncertainty.

The experience of HIV and AIDS information before and immediately after diagnosis for serodiscordant couples with asymptomatic HIV infection was full of shock and defeat. In this

state, the experience of HIV and AIDS information was affected by the availability of information relating to HIV and AIDS in general, and specifically on serodiscordance.

Couple #17 had lived with serodiscordance for seven years. They had engaged in HIV and AIDS activism to inform other couples about serodiscordance. They told me that one of their frustrations was the discontinuation of a newsletter from which they learned about serodiscordance. In this interaction with HIV and AIDS information it was experienced with confusion. According to Malawi National AIDS Commission (NAC) the newsletter was not discontinued but the responsibility for producing it was given to a partner organisation. In addition, NAC said there were no known information services for serodiscordant couples in Malawi (E. Kamanga, personal communication, March, 4, 2014). This corroborates assertions by serodiscordant couples presented in Chapter 7 that HIV and AIDS information relating to serodiscordance was not available. In addition, this suggests that people living with HIV and specifically serodiscordant couples were passive recipients of HIV and AIDS information. The implications, as demonstrated in this example, are that small changes like transfer of responsibility for an information service could mean a new target audience that leaves out some serodiscordant couples.

Evidence from interview conversations suggests that some serodiscordant couples evaluated HIV and AIDS information while interacting with it. This resulted in the continuation of the interaction or some HIV and AIDS information being filtered. A telling example was given by couple #7. The two partners in couple #7 were members of the Catholic Church and they constantly received or encountered HIV and AIDS information from the church which was against the use of condoms among married couples. The male partner said; "*for us couples with different HIV statuses we are encouraged to use condoms, but on the church side, as Catholics, we are not allowed, using condoms. So when we use condoms we use as disobedient people*".

Serodiscordant couples interacted with HIV and AIDS information intersubjectively. As presented in chapters 6 and 7 most serodiscordant couples interacted with HIV and AIDS information in lived places that were also inhabited with others. One participant commented: "*The difference is that at the hospital [ART clinic] we are a group and everyone is able to explain what they do to have a healthy life" (HIV+ Female partner, Couple #13).* In addition to physical information objects available in these places, most of the information was provided by health workers. Outside these places some partners in serodiscordant relationships shared HIV and AIDS information with their spouses and other people. The importance of participation in formal and informal social organisations for people living with HIV was investigated by C. Campbell et al. (2013). The study

found that participation in social organisations created opportunities for people living with HIV to engage in useful dialogue that assisted them to renegotiate social norms and reconstruct a new self.

Some serodiscordant couples' stories indicate that some HIV and AIDS information was not anticipated. This is illustrated in the description of how the HIV positive partner in couple #6 interacted with HIV and AIDS information in booklets he found people distributing. He said:

> *"Yes, I once got information in that manner, I found people distributing booklets concerning this disease. I received one of those booklets… " (HIV+ Male partner, Couple #6 separated)*

This excerpt demonstrates that serodiscordant couples could interact with HIV and AIDS information without anticipating it.

8.3.6   Acting on information

As defined by Kari (2001, p. 37) acting on information is "a process in which the individual performs meaningful deeds in relation to information and knowledge in order to achieve something". Based on evidence from interview conversations with serodiscordant couples information was also experienced when acting on it. Most of the HIV and AIDS information for serodiscordant couples was to be acted on by the two partners together. As such, it relied on the two partners to be committed to the adherence of what the information required of the couple. An example also discussed in chapter 7 (section 7.11) is condom use. The findings of my study suggest that male partners were in most cases reluctant to use condoms regardless of their HIV status. This example shows that some couples when acting on HIV and AIDS information experienced it with negative emotions. Other serodiscordant couples indicated that their religions did not allow condom use. As a result information about condoms was acted on with the guilt of sin.

When acting on HIV and AIDS information serodiscordant couples continually evaluated the information for religious and cultural relevance. HIV and AIDS information was also evaluated for its factual and practical correctness. One of the reasons given by serodiscordant couples for trusting certain sources of HIV and AIDS information such as the hospital was that they had tried and tested them. Another example is the experience of anxiety for female partners who were pregnant and acting on information to prevent transmission of HIV to their baby.

Evidence from interview conversations also suggests that some information was filtered while acting on it. The female HIV positive partner in couple #17 described how she stopped going to

one religious organisation's meetings after she was told by the leader of that organisation to separate from her husband. Prior to receiving this advice, she was acting on HIV and AIDS information provided by the organisation. Her narrative suggests that although she remained religious, all HIV and AIDS information from that particular religious organisation was filtered.

8.3.7   Reflection on information

Inherent in all the three stages of experiencing HIV and AIDS information described in sections 8.3.4, 8.3.5, and 8.3.6 was the fourth stage. This was the process of reflecting on HIV and AIDS information. In hindsight serodiscordant couples were able to re-live the experiencing of HIV and AIDS information. Most couples described the experience of HIV and AIDS information before the diagnosis. The fact that serodiscordant couples were able to describe how they experienced HIV and AIDS information suggests that they were re-living the experience. Talking about this issue a male HIV positive partner in couple #1 said; *"For me when I heard information that when you are found positive you take medication daily the rest of your life I was distressed. In fact, when I first heard it I was not distressed, but when I was found HIV positive and recalled that message I realised that this means that I will take medication daily the rest of my life, my heart was distressed"* (HIV+ Male partner, Couple #1). This excerpt suggests that the partner, after interacting with HIV and AIDS information for the first and found it irrelevant, he filtered it. He then reflected on the information after his circumstances had changed with the HIV infection. In addition, it suggests that he interacted with the HIV and AIDS information for the second time and found it relevant.

Thus results of this study suggest that HIV and AIDS information that was filtered during the anticipation, interaction, and acting stages was reflected on. Further, reflection resulted in some information which was filtered being interacted with. Serodiscordant couples were also found to interact with HIV and AIDS information they had interacted with previously. When reflecting on HIV and AIDS information serodiscordant couples were able to filter some information.

One motivation for reflecting on information filtered in the past was the change in HIV status. This suggests that the partners had internal HIV and AIDS information resources they were able to draw on before seeking from external sources to meet an information need. H. Bruce (2005) described what he called personal information collections. Personal information collection is defined as "the space we turn to first when we need information to do a task or pursue an interest" (H. Bruce, 2005). Further, Bruce notes that personal information collections are built through everyday contact with information sources or channels.

In the present study serodiscordant couples were also found to evaluate HIV and AIDS information they were reflecting on. This is evident in the case of couple #17 who had a collection of HIV and AIDS music. As quoted in sections 6.8 and 7.5 they described some HIV and AIDS songs in their collection as useless.

The five life-world existentials discussed in chapter 5 and section 8.2 in the present chapter tie in very closely with the four stages of experiencing HIV and AIDS information described in this section. As discussed in chapter 5, HIV and AIDS information was experienced through the lived body. Serodiscordant couples physically touched HIV and AIDS information materials and browsed or read through. In addition, couples listened and watched information items on radio, television, at ART clinics, VCT centres, in hospitals, and various HIV and AIDS information events. Therefore it was the couples in bodily form anticipating the information, interacting with it, acting on it, and reflecting on it. In their descriptions, serodiscordant couples suggest that information was experienced with others. Some HIV and AIDS information anticipated was to come from lived others. In addition, information was interacted with intersubjectively with relatives, other people living with HIV, and health workers. Likewise, some reflections on HIV and AIDS information were done in conversation with others. All information anticipation, interaction, acting on, and reflection took place in lived spaces. Besides, some information sources were lived spaces. Lived time was also closely linked to experiencing of HIV and AIDS information. When anticipating HIV and AIDS information couples were experiencing passage of lived time, and reflecting on information concerns an event that occurred in the past.
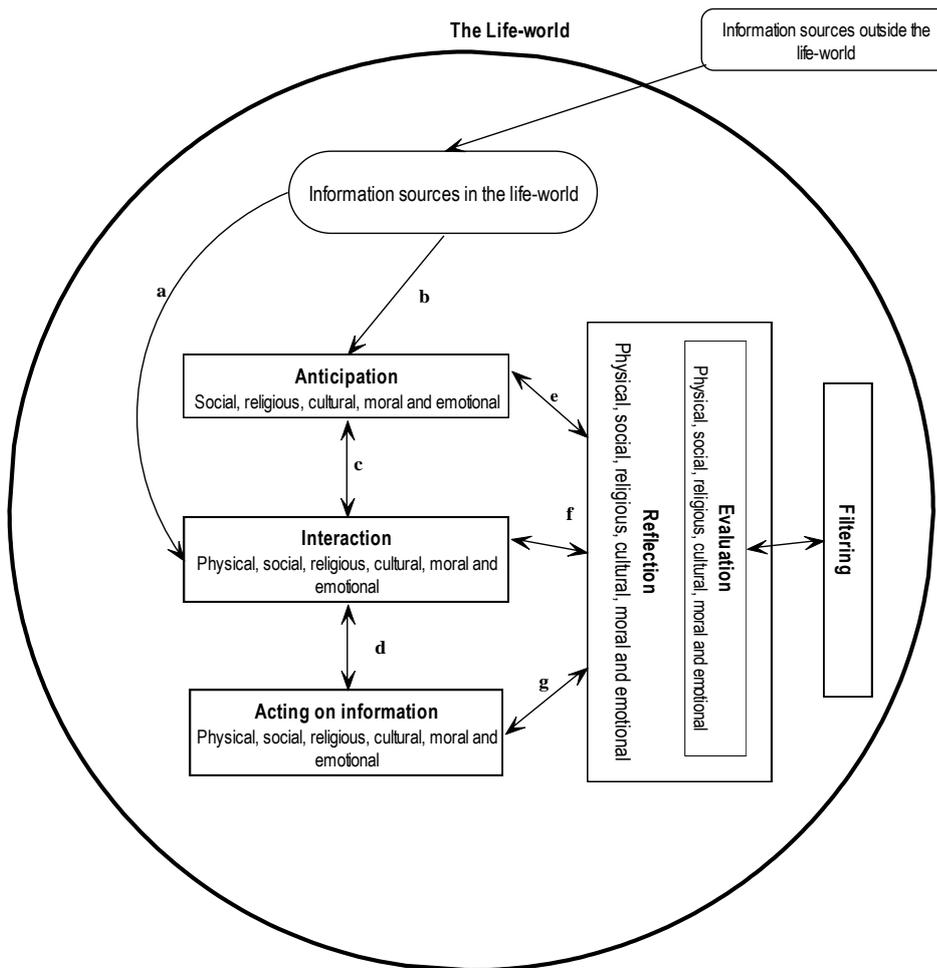
Figure 8.4: Conceptual framework for experiencing HIV and AIDS information

In the conceptual framework of experiencing HIV and AIDS information presented in Figure 8.4 the circle represent the five existentials of the life-world as discussed in chapter 5. Therefore, sources of HIV and AIDS information are viewed as external or internal to the life-world. In addition, all HIV and AIDS information, whether coming from sources internal or external to the life-world, are experienced within the life-world.

I will start by describing two processes that occurred in all four stages of experiencing HIV and AIDS information as represented in Figure 8.4. These are evaluation and filtering. In this present study, I conceptualised evaluation as a form reflection. As represented by arrows e, f, and g serodiscordant couples evaluated HIV and AIDS information in all stages of experiencing. Serodiscordant couples evaluated HIV and AIDS information for cultural and religious correctness and relevance. Information that was viewed as irrelevant or unsuitable was filtered (arrow h). Some information though relevant and suitable was also filtered as a strategy to cope with too much information. Bi-directional arrows e, f and g suggest three things. First, the arrows suggest

that couples proceeded to anticipate or interact with or act on HIV and AIDS information that was found to be relevant or suitable after the evaluation process. Second, the arrows suggest that couples returned to information that was evaluated and filtered and anticipated or interacted with or acted on or reflected on it again. Thirdly, the arrows suggest that reflection on HIV and AIDS information, as a fourth stage of experiencing information occurred at, and concurrently with the other three stages.

Serodiscordant couples first experienced HIV and AIDS information while anticipating it. The process of anticipating HIV and AIDS information had a social dimension since it occurred in the company of lived others. In addition, HIV and AIDS information appear to touch on cultural and religious issues. For instance, issues about sex and marriage were regulated by religious and cultural norms.

The second stage of experiencing HIV and AIDS information was when interacting with it. This involved paying attention to the information through reading, listening, browsing or watching. The process of interacting with HIV and AIDS information for serodiscordant couples was emotional. The emotions arose from the fact that the HIV infection brings the marriage union under scrutiny as HIV and AIDS information identifies unprotected sex as one of the primary means through which the virus is transmitted. Interacting with HIV and AIDS information involved interacting with physical objects such as books, newsletters, flyers, and brochures. Information was also interacted with through interaction with other people in religious organisations, VCT and ART centres. As represented by arrow a, some HIV and AIDS information was interacted with without anticipating it.

The third stage of experiencing HIV and AIDS information was while acting on it. Serodiscordant couples acted on HIV and AIDS information that was identified as essential to the management of the HIV infection. The bi-directional arrow (arrow d) suggests that the serodiscordant couples continued interacting with HIV and AIDS information while acting on it. Practically this means that they continued paying attention to the information while applying it to some aspects of their lives. Acting on HIV and AIDS information was described as an emotional experience for serodiscordant couples. Some HIV and AIDS information implied the imminent death of the HIV positive partner. For the HIV negative partner HIV and AIDS information was a constant reminder of the vulnerability of being in serodiscordant couple.

The fourth stage of experiencing HIV and AIDS information occurred concurrently with the stages of anticipation, interaction, acting on information, and interaction. Like in the previous stages information experience at this stage was also emotional. When reflecting on HIV and AIDS

information serodiscordant couples appeared to evaluate it for its effectiveness in satisfying their information needs. In addition to cultural and religious criteria mentioned in the preceding stages, information was evaluated for effectiveness at this stage. Reflection on HIV and AIDS information was an emotional experience as a result of the nature of HIV itself. As stated earlier, the bi-directional arrow e, f and g suggest that couples could go back to some HIV and AIDS information reflected on and anticipate more of it, interact with it, and act on it. This could be information filtered in the interaction stage.

8.3.8   Implications of the conceptual framework

I posit that design of information services should be driven by needs of the users of that service. The stages in the conceptual framework presented in figure 8.4 can be viewed as critical areas for intervention in order to facilitate positive experience of HIV and AIDS information. In order to avoid the "cart before the horse" situation (where information service design is driven by technology and not consumer needs) (Hepworth, 2007, p. 43) knowledge of the information experience of the user of the service need to inform the design process. In the context of Chatman's Theory of Life in the Round, people would not seek information if everything in their small world is going on well (Chatman, 1999). Therefore, the conceptual framework identifies critical stages of experiencing HIV and AIDS information where efforts to make people seek information can be focussed.

As demonstrated in the findings of my study, some serodiscordant couples were given HIV and AIDS information in formats that were not accessible to them. In addition, some serodiscordant couples found HIV and AIDS information coming from sources outside their life-world to be in a language they were not competent in. When the HIV and AIDS information was translated into their local language, they described the terminologies used as being culturally or morally insensitive. Albright (2007) suggests that HIV and AIDS information should be designed for specific target audiences in order to address cultural contexts, and language and format preferences.

As discussed in Chapter 7 some HIV and AIDS information on serodiscordance was unavailable. As such serodiscordant couples were anticipating information which was never to come. Therefore, knowing information needs of the couples would enable information service providers to respond by making available information resources to fill the gaps. On the other hand, some serodiscordant couples did not even trust the sources they anticipated HIV and AIDS information from. Findings of my study suggest that serodiscordant couples valued HIV and AIDS information that was provided by people who were also living with HIV. This finding resonates with

Namuleme's (2012) which suggests that people living with HIV value information provided by peers based on their experiences of living with HIV. This finding also re-enforces Hepworth's (2007) recommendation for participatory approaches in the design of information services in order to meet the needs of the user.

The conceptual framework highlights the need for ensuring a positive experience of HIV and AIDS information in the second stage (Interaction). The findings of my study suggest that serodiscordant couples received inconsistent explanations of the causes of serodiscordance. Some couples did not believe that serodiscordance is possible. Such characteristics of HIV and AIDS information can lead to uncertainty (Brashers, 2006). Brashers adds that because of doubt of the validity of information available one is not able to use it in decision making. In the context of the conceptual framework such information is likely to be filtered. It is therefore important to ensure consistence and correctness of information provided to serodiscordant couples.

I have demonstrated in the findings of my study that although the HIV statuses of the two partners were distinguishable as HIV positive and negative, their experiencing of HIV and AIDS information were not. Case (2012) suggests that when people that are health seek health information there might not be a sense of urgency. The information seeking might be motivated by mere curiosity and not to be used to make any decision. On the other hand, Bundorf, Baker, Singer, and Wagner (2004) assert that people in poor health or those with higher expectation of poor health are more likely to seek health information than those in good health. Based on the findings of my study I would argue that most HIV negative partners in serodiscordant couples in Malawi are categorised as healthy people. Therefore, most HIV and AIDS information service providers work on the presumption that information needs of HIV negative partners in serodiscordant couples will be satisfied by general prevention messages meant for the general population. As a result HIV negative partners feel discriminated and alienated when interacting with, and acting on HIV and AIDS information. A good example is described in Chapter 7 where HIV negative partners were considered as spies in HIV and AIDS support groups.

8.4 Chapter conclusion

This chapter has discussed the life-world as the context of experiencing HIV and AIDS information. The four existential of the life-world are discussed in as far as they contribute towards the experiencing of HIV and AIDS information. A fifth existential, spirituality is proposed. This fifth existential concerns the belief in God and ancestral spirits. The discussion of the life-world existential is crystallised by the visual presentation of life-world of serodiscordant couples. Taken together with results presented in chapter 5, the discussion of the life-world in this chapter

illuminates the interconnectedness of the serodiscordant couple, their life-world, and the experiencing of HIV and AIDS information.

The present chapter has also discussed what experiencing of HIV and AIDS information is like. Four stages of experiencing HIV and AIDS information have been identified and these are anticipation, interaction, acting and reflection. Further, the two concepts related to experiencing HIV and AIDS information were discussed with examples from the data.

In the next chapter, the experiencing of HIV and AIDS information will be discussed in the context of previous studies. In addition, the implications of the four stages of experiencing HIV and AIDS information will be discussed.

Chapter 9

Discussion of results

9.1   Introduction

The aim of this research was to investigate how serodiscordant couples experience HIV and AIDS information. In this chapter I will bring together the results presented in the three results chapters (Chapter 5, 6 and 7) with related literature including existing literature in the field as discussed in Chapter 2. This is followed by a review of the findings specifically in the context of Chatman's Theory of Life in the Round, and Wilson's 1996 Model of Information Behaviour.

9.1.1   Summary of findings

This present study investigated how serodiscordant couples experience HIV and AIDS information using in-depth interviews and observation in the serodiscordant couple's homes. The results of the study are summarised in table 9.1 and subsequently discussed. In the discussion of the findings, themes that are related will be discussed together. In addition, themes that are cross-cutting will be discussed alongside other themes throughout the chapter.

Table 9.1: Summary of findings

Major theme	Key finding	Reference
The life-world	The life-world is the overarching framework of experiencing HIV and AIDS information for serodiscordant couples	See chapter 5
Serodiscordant couples' needs	Serodiscordant couples had needs that triggered HIV and AIDS information needs	See chapter 6; Sections 6.2 to 6.7
Experiencing HIV and AIDS information sources	Serodiscordant couples had four categories of HIV and AIDS information sources	See chapter 6; Section 6.8
	Serodiscordant couples experienced HIV and AIDS information sources before experiencing the information	See chapters 6 & 7; Sections 6.9 to 6.12; 7.2
Availability and accessibility of HIV and AIDS information	HIV and AIDS information was experienced as available or unavailable, and accessible or inaccessible	See chapter 7; Section 7.3 (sub-sections 7.3.1 & 7.3.2)
Decision making guide	HIV and AIDS information was experienced as decision making guide	See chapter 7; Section 7.4
Information standards	HIV and AIDS information was experienced based on information standards	See chapter 7; Section 7.5
Emotions	HIV and AIDS information was experienced with negative emotions	See chapter 7; Section 7.6.1
	HIV and AIDS information was experienced with positive emotions	See chapter 7; Section 7.6.2
	HIV and AIDS information was experienced with ambiguous emotions	See chapter 7; Section 7.6.3
Denial	HIV and AIDS information was experienced with denial	Chapter 7; Section 7.7.1

Despondency	HIV and AIDS information was experienced with despondency	Chapter 7; Section 7.7.2
Moral and religious values	Moral and religious values affected the experience of HIV and AIDS information	See chapter 7; Section 7.8
Culture	HIV and AIDS information was experienced within the cultural milieu of the serodiscordant couples	See chapter 7; Section 7.7
Gender	Gender affected the experience of HIV and AIDS information.	See chapter 7; Section 7.12
Social networks	HIV and AIDS information was experienced within social networks	See chapter 7; Section 7.11

9.2   HIV and AIDS information

I will start this section by revisiting the definition of "information". Instead of discussing the general definition of information I will reflect on what constituted HIV and AIDS information for serodiscordant couples. As presented in sections 5.2 and 8.2.1 the first experience of HIV for the serodiscordant couples was through the lived body. Therefore, in this study the lived body is identified as an important source of HIV and AIDS information. HIV and AIDS information was also conceptualised as facts about HIV and AIDS from physical items such as books, newsletters, brochures, flyers and personal health records. Additionally, facts, views and opinions about HIV and AIDS in radio and television broadcasts, and music were also considered information. Further, serodiscordant couples described talks by nurses, VCT and ART counsellors as useful HIV and AIDS information.

HIV and AIDS information was also conceptualised as subjective socially constructed views and opinions about HIV and AIDS. In this case every day talk with and by peers was considered to be HIV and AIDS information. In addition, serodiscordant couples considered actions that communicated certain aspects of HIV and AIDS as HIV and AIDS information. For instance, in Chapter 6 (section 6.8) I discussed about a male partner in a serodiscordant relationship who felt discriminated against every time he saw people avoiding people injured in an accident for fear of being infected with HIV.

In this study I have described how experiences of living with HIV were used to encourage others to go for HIV testing. Some serodiscordant couples consulted other couples who were living with serodiscordance for advice on how to manage their situation. What is clear from my study is that these experiences were considered to be information.

These conceptions of HIV and AIDS information are consistent with observations by Mathiesen (2004) that there seems to be no agreed definition of 'information' across different disciplines. In the context of my study, **information was stimuli, heard, seen, tasted, and felt, that played a role in formation of perceptions, beliefs, and attitudes about HIV and AIDS**.

Serodiscordant couples in my study described HIV and AIDS information as being complex, with terminologies that were not properly translated into the local language. In addition, some couples were overwhelmed with the evolving nature of HIV and AIDS information. My findings accords with the features of HIV and AIDS information identified in the review of literature in chapter 2. HIV and AIDS information is described as being complex, uses diverse terminologies, and is growing at an "epidemic rate" (Huber and Gillaspy, 1998, p. 191). These findings taken together with previous studies points to features that may be problematic to people who have little or no formal education like the serodiscordant couples I studied. These people may not have sufficient skills to interact with complex and evolving HIV and AIDS information regarding a complex phenomenon such as serodiscordance.

9.2.1   HIV and AIDS information sources

Serodiscordant couples in the present study used various sources to access HIV and AIDS information. As presented in chapter 6 (section 6.8), I categorised information sources as personal or impersonal, and formal or informal. In addition, information sources were also viewed as residing within or outside the life-world.

The first important source was HIV and AIDS support groups. All HIV positive partners reported membership of an HIV and AIDS support group. However, findings of this study suggest that some HIV negative partners were rejected from HIV and AIDS support groups as they were considered to be spies. The social dynamics in the this finding resemble the notion of homophily as described by McPherson, Smith-Lovin, and Cook (2001). Homophily is a natural tendency for people to bond with others who are similar in terms of "demographic, behavioural, and intrapersonal characteristics" (McPherson et al., 2001, p. 415). McPherson et al. contend that "homophily limits people's social worlds in a way that has powerful implications for the information they receive, the attitudes they form, and the interactions they experience" (p. 415).

A study by Ramlagan et al. (2010) confirms that people living with HIV expect that members of HIV and AIDS support groups to be only HIV positive people. In addition, Ramlagan et al. confirm that members of support groups expect that if HIV negative people, who are affected by HIV, join the groups, they need to keep confidential all discussions in the support group. Like in Chatman (1996) study, my study identified a worldview shared by people living with HIV. It is a world in which they did not believe that HIV negative people were good sources of HIV and AIDS information. This led to a form of classification that created a divide between HIV positive and negative people. HIV positive people were more willing to share HIV and AIDS information with peers of their type. This caused HIV negative partners in serodiscordant couples to live on the

fringes, between two worlds. Chatman argues that in a small world, insiders are always suspicious of outsiders as they doubt the outsiders' ability to understand their world. In the present study the people the two partners interacted with had implications on their attitudes towards each other and the serodiscordance. In addition, interactions with other people contributed to the type and quality of HIV and AIDS information they received.

Another source of HIV and AIDS information that was mentioned by some serodiscordant couples was music. As observed in the results of this present study, music as a source of HIV and AIDS information appears not to be regulated. Some serodiscordant couples noted that some HIV and AIDS songs that were composed by some Malawian musicians carried what they thought were wrong HIV and AIDS information. Such songs were experienced with negative emotions because most of such songs blamed people living with HIV as being promiscuous. On one hand, this finding contradicts Bastien (2009) who investigated the role of music in communicating HIV and AIDS information. Bastien's study only focussed on the positive contribution of music in communicating HIV and AIDS information. Bastien reported that music was influential in communicating HIV and AIDS information in a culturally appropriate way. However, some HIV and AIDS related songs mentioned by serodiscordant couples during the interviews contributed to the negative experience of HIV and AIDS information. Lwanda (2011) argues that some lyrics of HIV and AIDS songs by male musicians in Malawi had misogynistic views. Further, Lwanda contends that lyrics of most HIV and AIDS songs show that musicians had erroneous knowledge of the pandemic. Results of my study suggest that some sources of HIV and AIDS information are not regulated and as a result information coming from such sources can be wrong.

One important finding in this study was the use of the lived body by serodiscordant couples as a source of HIV and AIDS information. In addition to being itself information, this awareness prompted the patients to seek information from other sources. On the other hand, people used signs associated with HIV they saw on the lived body to make lay diagnoses. Although, most partners in serodiscordant couples in my study looked physically healthy, the knowledge that the HIV positive partner's body was inhabited by HIV affected the way they presented their bodies in social interaction. The findings of my study suggest that most serodiscordant couples had a feeling that people were able to tell that they had HIV understandably so because of the way the lived body was presented in HIV and AIDS information. The lived body was the subject of most narratives in HIV and AIDS information. As presented in chapter 6 (see figure 6.1), some HIV and AIDS information contained graphic images of how an HIV positive person's body looks like. This resonates with Cooley (1922)'s description of the presentation of the lived body in society. Cooley uses the metaphor of the looking glass to demonstrate how the conception of 'self' comes about

in society. Cooley maintains that the 'self' has three elements which are "the imagination of our appearance to the other person; the imagination of his judgment of that appearance, and some sort of self-feeling, such as pride or mortification" (p. 185). A study by Lloyd et al. (2013) also confirms that people living with chronic illness use their bodies as a point of reference for their awareness of the illness and the changes it caused in the body.

My study highlights the significance of the lived body for the two partners in a serodiscordant couple. In addition, my findings bring to fore the sense of confusion that is experienced by serodiscordant couples regarding seemingly contradictory HIV and AIDS information. In the mainstream HIV and AIDS information the HIV infected body is presented as an infectious body that needs to be sexually avoided. On the other hand, serodiscordant couples were told that it was possible to stay together without the HIV negative partner getting infected. In the sexual relations the two partners embodied their marital union yet it was an act of vulnerability. Howson (2004) argues that in any social interaction the actors need to present themselves with corporeal integrity. Findings from my study and observations during interviews indicate that HIV and AIDS information was used to cast doubt on the integrity of HIV positive partners as faithful spouses.

The body of the HIV partner was informative to the HIV negative partner and others of the effects of HIV infection. In addition, the findings of the present study suggest that conceptions of the HIV infected body were based on how it was presented in HIV and AIDS information. The HIV positive partners felt changes in their bodies which they described as weakness, headache, sores, or weight loss. It is HIV and AIDS information that was available to the serodiscordant couples that assigned meaning to these changes. In chapter 8 (section 8.2.1) I noted that serodiscordant couples needed insights into the language of the lived body in order to understand HIV and AIDS information it provides. I suggest that HIV and AIDS information from other sources such as ART and VCT clinics can facilitate the development of skills to understand information from the lived body.

The lived body can also be viewed in the context of lived time. HIV infection appears to represent what the HIV positive partner had done in the past. In addition, what was done in the past appear to affect serodiscordant couples' present lives, and reduce their longevity. Thus my study identifies three lived time horizons that HIV and AIDS information has to deal with. Evidence from my study suggests that most HIV and AIDS information that addressed the past lived time horizon used language that blamed people living with HIV for being promiscuous. On the other hand, HIV and AIDS information that addressed the present horizon focussed on HIV prevention. HIV and AIDS information that addressed the future horizon aimed to foster positive living with HIV. These

three horizons of lived time were used by serodiscordant couples to re-interpret the present status of the lived body based on what was done in the past in order to plan for the future. Based on Van Manen's (1997) commentary on these lived time horizons, I posit that serodiscordant couples need information resources that would assist them to positively deal with the three lived time horizons positively.

As presented in chapter 6 (section 6.8), the results of the present study suggest that serodiscordant couples preferred personal sources of HIV and AIDS information. Although, serodiscordant couples had access to HIV and AIDS information in print and broadcast on radio and television, informal personal sources were consulted first. A similar finding was reported by Hogan and Palmer (2005) who found that people living with HIV preferred personal sources of HIV and AIDS information. This finding suggests that personal sources had some desirable attributes that made them attractive to serodiscordant couples in my study. Where couples in my study had misgivings about personal sources, they identified undesirable attributes. Personal sources of HIV and AIDS information were preferred for being able to offer opportunities to interact and ask questions. However, some personal sources were criticised for lack of empathy and lived experience of the disease. Based on these findings I identify some desirable characteristics for information sources for serodiscordant couples. These are ability to interact with the couples, and empathy. In addition, this finding suggests that there is need for participatory approaches to the design of HIV and AIDS information services in order to benefit from their experiences of living with HIV.

Although some studies on information seeking of people living with HIV identified internet (Hogan and Palmer, 2005; Kalichman et al., 2002) and libraries (Huber and Cruz, 2000; Kalichman et al., 2002) as sources of HIV and AIDS information, this present study did not. This confirms the findings of Malawi National Survey of Adolescents (MNSA) which reported that internet was not mentioned as a preferred source of sexually transmitted infections information. The survey also found that less than 1% of adolescents in Malawi had ever used internet (Munthali et al., 2006b). On the other hand, Elbert et al. (2011) reported in their study that public libraries in Africa are mainly used by young people aged between 16 and 30 years. In addition, 90% of library users used it for education. Making inferences from these previous studies I would argue that the non-use of library services in my study is due to lack of library services in Malawi that are relevant to information needs of serodiscordant couples. There also appear to be lack of actual library services provision in most rural areas in Malawi.

9.2.2 Reflection on theories of information behaviour

As stated in chapter 2, Wilson's Model of Information Behaviour, and Chatman's Theory of Life in the Round were identified and used in conceptualising this study. As stated by Glanz et al. (2008) the aim was not to test or measure or modify the theories. In this section I will look back at the results of this present study in the context the two theories of information behaviour. The two theories were reviewed in Chapter 2. The theories will now be discussed in as far as the results of the present study reflect the framework of the theories.

9.2.2.1 Wilson's Model of Information Behaviour

Wilson's Model of Information Behaviour provides insight into "the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use" (Wilson, 2000, p. 49). This includes the contextual issues that shape the information behaviour of serodiscordant couples. As demonstrated in figure 9.1 many elements of Wilson's Model of Information Behaviour were evident in the information activities of serodiscordant couples in the present study.

The present study has established that context was important to experiencing of HIV and AIDS information for serodiscordant couples. The discussion of the life-world of serodiscordant couples in Chapter 5 lays out the context in which HIV and AIDS information was experienced by serodiscordant couples. According to Wilson's Model of Information Behaviour, information need is conceptualised in some context. In the present study, serodiscordant couples started actively seeking information because of the illness of one partner. Most couples conceded that at this point they were not looking for HIV and AIDS information as they perceived their risk of being HIV positive as being very low. However, evidence presented in the results chapters indicated that there were some partners, based on the risky behaviour of their spouses, who were seeking HIV and AIDS information from the beginning of their illness.

Consistent with Wilson's Model of Information Behaviour, the present study found that serodiscordant couples encountered activating mechanisms and intervening variables. For most partners information seeking was activated by illness and fear of imminent death. On the other hand, it was mandatory for pregnant women in Malawi to get tested for HIV. Findings from the present study indicate that women who or their partner were found positive were eager to find more HIV and AIDS information relating to transmission of mother to child. In Wilson's model these are represented as stressors. As identified in Figure 9.1, some HIV and AIDS information also acted as stressors. Findings of my study suggest that serodiscordant couples used HIV and

AIDS information to cope with stress that arose from serodiscordance. Some couples turned to religious organisations which were also identified as sources of HIV and AIDS information.

As stated by Wilson (1999) there are other factors that can act to prevent the activation of information searching or prevent information use after it has been acquired. Findings of my study suggest that serodiscordant couples experienced intervening variables that prevented information searching such as cost of transport to where information was available, being restricted by spouse, and language barriers. In addition, my study also identified role related intervening variables such being a spouse, being a parent, or work related responsibilities. Specifically, some partners were encouraged to or prevented from seeking information by their spouses. Other couples were driven to seek HIV and AIDS information in order to prevent transmission to their baby.
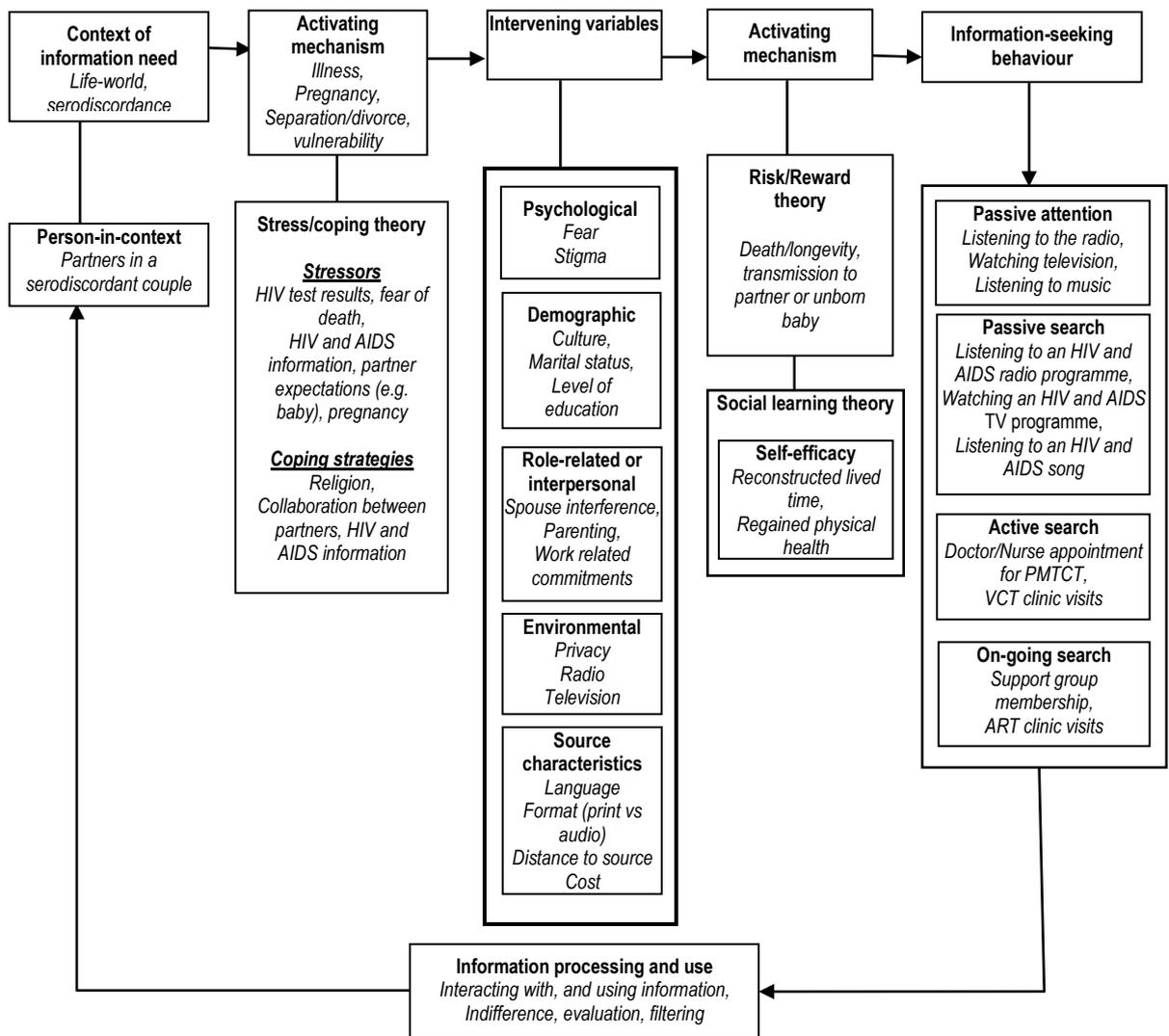
Figure 9.1: Wilson's (1996) Model of Information Behaviour adapted to experience of HIV and AIDS information. Adapted with permission from publisher from: Wilson, T. D. (1999). Models in information behaviour research. *Journal of Documentation, 55*(3), 249-270.

As presented in figure 9.1 a second set of activating mechanisms in relation to risk/reward theory, social learning, and self-efficacy were identified for the serodiscordant couples. After diagnosis couples were faced with the risk of death which was clearly described in HIV and AIDS information. As discussed in chapter 8 (section 8.2.2) HIV and AIDS information that stated that HIV has no cure, and the likely outcome of HIV infection is death was experienced with fear and anxiety. When one partner was diagnosed with HIV most serodiscordant couples described their lived time as truncated. These couples' self-efficacy was low. However, couples that had lived with serodiscordance for a long time experienced a reconstructed lived time, and high self-efficacy. Similarly, couples where the HIV positive partner had regained physical health because of ART had a positive outlook of the future.

Wilson and Walsh (1996) identifies four forms of information seeking behaviours: passive attention, passive search, active search, and on-going search. These behaviours have parallels

with the information seeking behaviours I identified among serodiscordant couples. Serodiscordant couples described moments of encountering HIV and AIDS information while passively listening to the radio or watching television. However, they mentioned specific radio and television programmes as important sources of HIV and AIDS information. Listening to and watching the programmes was a passive search for HIV and AIDS information. Information was actively searched by visiting doctors, nurses, and VCT clinics. In addition, serodiscordant couples were engaged in on-going search for HIV and AIDS information through their membership to support groups, and routine visits to ART clinics.

The discussion in this present section draws attention to the significance of Wilson's (1996) model in the design of HIV and AIDS information services in general, and specifically for serodiscordant couples. Figure 9.1 moves on to reflect on the significant information service design components. At a practical level Wilson's (1996) model, populated with findings from my study, identifies a path-way for HIV and AIDS information material design with critical points of intervention. For example, the focus is on the person in context, in this case, partners in a serodiscordant couple. In addition, it identifies the factors that motivate serodiscordant couples to seek HIV and AIDS information, and factors that can prevent or encourage information seeking.

The findings of my study draw attention to existence of factors that prevented information use after it was successfully obtained. A good example reported in my study is female partners who were prevented from acting on HIV and AIDS information by their spouses. In the context of the framework of experiencing HIV and AIDS information presented in figure 8.4 these factors made female partners in serodiscordant couples to filter information after they had interacted with it. However, this finding identifies a gap in Wilson's (1996) Model of Information Behaviour. In the model, the intervening variables only affect information seeking at the beginning only. As argued by Niedźwiedzka (2003) intervening variables are in operation throughout the process.

9.2.2.2 *Chatman's Theory of Life in the Round*

Chatman's "theories support a close analysis of situations... in which different small worlds intersect; leading to conflicts and misunderstandings between groups" (Burnett et al., 2008, p. 4). The present study has identified several lived spaces that could be classified as small worlds in the context of Chatman's theory, which were occupied by serodiscordant couples. Serodiscordant couples occupied the home which was considered as a safe place. However, the findings of my study suggest the home as a small world intersected with the larger community. First, in accordance with traditional marriage practices in many Malawian cultures, serodiscordant couples' decisions on reproductive health, including condom use, were influenced by members of

the extended family. Secondly, other people living in the same community as the serodiscordant couples influenced their experience of HIV and AIDS information. Every day talk about HIV and AIDS influenced the two partners' opinion about HIV and AIDS, and their interaction in the home. As stated by Chatman (1999), social norms are part of the social fabric and set the boundaries within which people play out their lives. In addition, Chatman argues that popular opinion in any small world can define an individual's actions.

As is the case with all small worlds, the communities in which serodiscordant couples in this present study lived were defined by cultural, geographical and social boundaries. This study has found that within the communities there was social typing. A good example was provided by a couple who described how people avoided their home because of the HIV infection. In addition, most serodiscordant couples were surprised with their diagnosis as they believed that HIV was a disease for other social types; prostitutes and unmarried adults. Therefore, HIV and AIDS information was viewed as for those social types.

Another important finding of the present study was that HIV negative partners were rejected in some small worlds. HIV positive people considered themselves the exclusive patrons of HIV and AIDS support groups. In the context of Chatman's theory of information poverty HIV negative partners were considered as outsiders. According to Burnett and Jaeger (2008) small worlds have a natural tendency to "closely guard aspects of their own norms or worldviews from outsiders, trying to keep other small worlds, or the life world as a whole, from gaining access to such secrets". Because of the stigma and discrimination they experienced, people living with HIV internalised their social type and considered the HIV and AIDS support groups are their safe place. In addition, Chatman (1999) states that human beings tend to reveal and share information with people of their social type. Therefore in the present study it was natural for HIV positive people to regard HIV negative partners in serodiscordant relationships as outsiders. Chatman's theory resonates with my earlier discussion of the concept of homophily in section 9.2.1.

The other similarity between my results and Chatman's Theory of Life in the Round is in the absence of active information seeking before the HIV infection. Chatman argues that people in a small world will not seek information as long as everything is going alright. Most serodiscordant couples I interviewed confessed that they were not actively searching for HIV and AIDS information before the HIV infection. Related to this, another finding of my study suggests that in some serodiscordant couples only the HIV positive partners were actively searching for HIV and AIDS information. This then contradicts Chatman's theory in that although the HIV negative partners in these couples knew that things were not alright in their small world, they never

searched for information. A possible explanation is that these partners avoided HIV and AIDS information as a strategy to cope with the illness of their spouse. This explanation is supported by findings by Narayan et al. (2011) who found that some people would actively avoid personal health information about a condition they vaguely know for fear of being depressed and changing their way of life.

Like life in Chatman's small world life for serodiscordant couples was full of imprecision and uncertainty. In my study, some HIV negative partners were told that their test results were not final as the virus could have been hiding. As a result they lived a life of imprecision and uncertainty with some wrongly concluding that they were infected. In chapter 5, I gave an example of an HIV negative partner who was asking himself what his future would be like, and what he should do to live a longer life.

The discussion of the present study presented in this section identifies two regions of the world of serodiscordant couples. The first region was inside their small world and the other outside of it. Similar to Chatman's small world, serodiscordant couples appeared to seek information from within their small worlds first before seeking from sources outside. My study found that within their small world serodiscordant couples got HIV and AIDS information from family, friends, other serodiscordant couples, religious leaders, and traditional doctors. When this information was not effective in solving their problems, couples appeared to seek information from outside their small world. However, there is evidence in my study that HIV and AIDS information from outside was filtering into the small world through community health workers, and HIV and AIDS information campaigns. Although HIV and AIDS information that filtered into the small world from formal sources had potential to change negative opinions, beliefs, and prejudices about HIV and AIDS, my study did not find evidence of deliberate efforts to achieve this.

Another important finding of this study that resonates with Chatman's Theory of Life in the Round is the social situatedness of experiencing HIV and AIDS information. Chatman (1999) observes that some information is considered noteworthy because it is produced in a specific context to be used in that context. Most serodiscordant couples in my study were influenced by HIV and AIDS information from family and friends because it was relevant to their worldview and social norms. Lloyd (2012) argues that information behaviour is different in different social settings. Lloyd further contends that people in a particular social setting form a mutual understanding of what constitutes valuable information and ways of knowing. This finding re-enforces the importance of the life-world as the context of experiencing HIV and AIDS information.

I will conclude this discussion of Chatman's Theory of Life in the Round by reflecting on the theory's six propositions in the context of the findings of my study.

Proposition 1: *A small world conceptualization is essential to a life in the round because it establishes legitimized others (primarily "insiders") within that world that set boundaries on behaviour.*

The findings of the present study suggest that serodiscordant couples' lives played out in small worlds. Consistent with Chatman's theory, small worlds in my study had legitimised 'insiders'. As described in this present section HIV positive partners were considered 'spies' in HIV and AIDS support groups, and HIV was considered a disease for prostitutes.

Proposition 2: *Social norms force private behaviour to undergo public scrutiny. It is this public arena that deems behaviour—including information-seeking behaviour—appropriate or not.*

When one partner in a serodiscordant couple was diagnosed with HIV, the couples' private sexual lives underwent public scrutiny. As stated by Howson (2004) HIV and AIDS is considered as a disease and condition that result from living certain life-styles.

Proposition 3: *The result of establishing appropriate behaviour is the creation of a worldview. This worldview includes language, values, meaning, symbols, and a context that holds the worldview within temporal boundaries.*

Findings of my study indicates that in the small worlds serodiscordant couples lived, appropriate behaviour was defined based on religious, cultural, and moral values. Condom use was considered inappropriate behaviour for married couples, and HIV and AIDS information was viewed as too explicit to be broadcast on radio.

Proposition 4: *For most of us, a worldview is played out as life in the round. Fundamentally, this is a life taken for granted. It works most of the time with enough predictability that, unless a critical problem arises, there is no point in seeking information.*

My study has demonstrated that before diagnosis of HIV most serodiscordant couples took their healthy bodies for granted and they were not seeking information.

Proposition 5: *Members who live in the round will not cross the boundaries of their world to seek information.*

This proposition follows on proposition 4. Chatman (1999) states that if their world is working without it, people in a small world have no reason to seek information. In my study, even when

one partner was ill, most serodiscordant couples did not immediately go for HIV testing. Information was sought from within the small world from traditional doctors, family and friends.

Proposition 6: *Individuals will cross information boundaries only to the extent that the following conditions are met: (1) the information is perceived as critical, (2) there is a collective expectation that the information is relevant, and (3) a perception exists that the life lived in the round is no longer functioning*

For serodiscordant couples, the three conditions described by Chatman (1999) were met when information obtained from family, friends and traditional doctors did not satisfy their needs. When most sources within their small world provided less useful information about their illness, serodiscordant couples had reason to cross the boundaries and look for information from ART and VCT clinics, and HIV and AIDS support groups.

9.2.3   Serodiscordance and HIV and AIDS information

My study has found that in Malawi there is a dearth of HIV and AIDS information addressing the phenomenon of serodiscordance. This finding was confirmed by Malawi National AIDS Commission who stated that there was no known HIV and AIDS information service targeting serodiscordant couples (E. Kamanga, personal communication, March, 4, 2014). Consistent with this finding, World Health Organisation and Joint United Nations Programme on HIV/AIDS (2009) identified that although a larger percentage of new HIV infections in many African countries occur among serodiscordant couples, there was very few HIV prevention programmes targeting this group. In addition, my study casts doubt on the universality of HIV and AIDS knowledge in Malawi. It appears that Malawians have universal knowledge on the general aspects of the pandemic. However, knowledge about couple specific aspects of HIV and AIDS appear to be limited.

Another result of the present study suggests that serodiscordant couples were not satisfied with the reasons given by health workers for their different HIV statuses. Serodiscordant couples were told that the negative HIV test result for the negative partner was because the virus was hiding or that the partner was infected but the viruses had not reached detectable levels. A possible explanation of this finding is that the explanations given by health workers were more speculative than factual. Therefore, my study draws attention to the need for standard information materials that provides facts about serodiscordance. Further, these findings identify the need for health workers to be up-to-date on serodiscordance.

The concept of 'serodiscordance' is poorly understood (World Health Organization, 2012) and insights into the dynamics of serodiscordant relationships are also limited (Persson, 2013). In Malawi, an assessment of the information needs of health workers found that there was lack of access to up-to-date health information in reproductive health, and HIV and AIDS (Sikwese and Management Sciences for Health, 2009). This result is corroborated by another study conducted in Malawi by LeMay and Bocock (2012) who found that health workers at the community level in Malawi lack access to up-to-date information materials on reproductive health, and HIV and AIDS. Furthermore, LeMay and Bocock found the community health workers continued to use outdated guidelines or protocols even when new ones had been introduced at the higher levels of the health system. Therefore, it follows that if health workers have poor access to health information, including HIV and AIDS information, they will be unable to effectively explain complex concepts such as 'serodiscordance'.

Results of this study presented in chapters 5, 6 and 7 suggest that couples expected people working in hospitals, ART and VCT centres to have all information they needed. Although health workers explained the cause of serodiscordance, serodiscordant couples were not satisfied. A good example was provided earlier in this section where most couples were told that the virus was 'hiding'. Similar findings were reported by Bunnell et al. (2005) in their study of knowledge, challenge and prevention strategies of serodiscordant couples in Uganda. The study found that HIV counsellors gave three reasons for serodiscordance. These were that the HIV negative partner was infected but the virus was hiding, the HIV negative partner was immune to HIV infection, and that the couple only had gentle sex. World Health Organisation and Global Health Workforce Alliance (2010, p. 24) contends that "[community health workers (CHW)] in general were not given a comprehensive training on the issue of HIV-prevention, treatment and rehabilitation. CHWs were not armed with rehabilitative strategies that would help them ease the life of HIV patients who are generally living with the social stigma related to the disease".

World Health Organization et al. (2011) identify unprotected sex as the major means through which HIV is transmitted. In light of this fact, serodiscordant couples in my study were surprised that only one partner was HIV negative. I therefore, posit that unavailability of HIV and AIDS information on serodiscordance had a multidimensional effect on the management of HIV. First, before diagnosis the couples had a low risk perception. Therefore, all HIV and AIDS information was viewed as being relevant for people that were HIV positive or for sex workers. Secondly, when one partner was found HIV positive, the other partner resigned to their fate because HIV and AIDS information implied that one would be infected with HIV if they had unprotected sexual contact with an HIV positive person. Thirdly, HIV positive partners in serodiscordant couples were

presumed promiscuous and blamed for the infection. As a result three scenarios emerged from my analysis. The first scenario is some serodiscordant couples separated and never reconciled. The second scenario is couples that separated and reconciled. These couples cited HIV and AIDS information from ART or VCT clinic and hospital as the eye opener that changed their perspective on serodiscordance. The third scenario is couples where both partners worked in unison to manage the serodiscordance. These couples too cited correct HIV and AIDS information obtained from ART or VCT clinic and the hospital.

9.2.4   Language and translation of HIV and AIDS information

One of the issues that emerged from the findings of this study is the language used as a medium of communicating HIV and AIDS information. Kamwendo (2008) observes that although Malawi is linguistically categorised as English-speaking the majority of people cannot competently read or write that language. Therefore, English is not the best medium for communicating HIV and AIDS information or as an aid to learning. This means that HIV and AIDS information, which is largely available in English, has to be translated into local languages. Additionally, findings of this study suggest that there are other partners who could not even read HIV and AIDS information in the local languages.

As reported in the results chapters, some serodiscordant couples noted that when some HIV and AIDS concepts were translated from English to Chichewa they became ambiguous. A good example given by one serodiscordant couple was 'antiretroviral therapy' which when translated into Chichewa is '*mankhwala otalikitsa moyo*' (life prolonging drug). 'Life prolonging' was thought to be labelling and have a connotation that life had ended, and only supported by medication. This finding is consistent with findings of a study conducted in Tanzania by Ezekiel et al. (2009). Ezekiel et al. investigated how antiretroviral therapy is understood and constituted in everyday talk. Among the terms identified in the study that were used to refer to antiretroviral therapy was 'life prolonging drugs'. Ezekiel et al. observed that the term, as it is used in Tanzania, has negative connotations. The term was found to suggest that people on antiretroviral therapy were destined to die and merely prolonging life. My findings suggest that when HIV and AIDS information used such terminologies, it caused serodiscordant couples to live a hopeless life. From the point of view of lived time, some HIV positive partners stopped investing in the future as they believed that their death was imminent. Experiences of less positive HIV and AIDS information appeared to be counterproductive to the positive contributions of good HIV and AIDS information had on serodiscordant couples. During the interviews I could sense frustrations among some serodiscordant couples. They criticised designers of HIV and AIDS information

materials for not piloting the messages on them to identify the language problems before full implementation.

The problem of translating HIV and AIDS information from English to African local languages has been widely researched (Kamwendo, 2008; Lubinga and Jansen, 2011; Namyalo, 2010). In her study, Namyalo (2010) referring to Luganda[5] noted that there is unstable development of HIV and AIDS terminology in African languages. While appreciating that this is characteristic of the development of terminology in any language, Namyalo argues that this is undesirable for HIV and AIDS terminology where there is urgency for HIV and AIDS information to combat the pandemic. Additionally, Kamwendo (2008) observed that there was lack of culturally appropriate HIV and AIDS terminologies in Malawian languages. This was confirmed in a study by McCreary, Kaponda, Davis, Kalengamaliro, and Norr (2013) which investigated how participation in HIV and AIDS peer leader intervention changed personal HIV-related knowledge, attitudes, and behaviours. One important finding was that before participation in the intervention the peer leaders thought HIV and AIDS messages were using foul language and as a result they took no interest in them.

This flags up a further issue relating to translation of HIV and AIDS information from English to local languages which is the use of culturally unacceptable terminologies. The current study found that some serodiscordant couples, especially of the older generation, were uncomfortable with some HIV and AIDS information. Some HIV and AIDS messages were found to be too explicit for broadcasting on radios. Furthermore, these couples said that they felt uncomfortable when certain HIV and AIDS messages came up on the radio in the presence of their children. This means that they would not discuss such HIV and AIDS related information with their children. Cain et al. (2011) observe that in African cultures language related to sex and sexuality that "is permissible varies dramatically in public and private settings, among single and mixed gender groups, among older and younger people and for the objectives of titillation versus education". Cain et al. investigated the culturally acceptable sex terminologies among Xhosa people in South Africa. The findings of the study indicate that the Xhosa people share a common cultural understanding of which terms are more appropriate than others when talking about sex and sexuality. Further, Cain et al. argue that HIV and AIDS information should pay careful attention to gender, politeness and specificity.

---

[5] A language spoken in Uganda

My study draws attention to the need for technically correct and socially acceptable terminologies to be used in HIV and AIDS information materials. The fact that Joint United Nations Programme on HIV and AIDS developed and maintains guidelines on HIV and AIDS terminologies (Joint United Nations Programme on HIV/AIDS, 2011) underscores the importance of this finding. Although there are these standard terminologies, my study identifies the need to adapt them to national and local contexts. Some participants in my study were particularly frustrated with the disregard for cultural values in HIV and AIDS materials.

9.3   Experiencing HIV and AIDS information intersubjectively

The results of this study indicate that serodiscordant couples experienced HIV and AIDS information intersubjectively. In Malawi marriage involves a wide network of extended family members from both the man's and woman's side. With customary marriages the extended family members have some influence on the marriage dynamics. In the current study some serodiscordant couples reported about the influence of marriage counsellors on decisions regarding the management of their HIV infection. Specifically, evidence suggests that one couple separated after marriage counsellors from the wife's side intervened in the marital dispute arising from the HIV infection. This indicates that serodiscordant couples experienced HIV and AIDS information within social network of the extended family.

Beyond their families serodiscordant couples experienced HIV and AIDS information with other people living in the community. Evidence presented in this present study suggests that serodiscordant couples viewed their bodies as child bearing bodies. The findings further indicate that serodiscordant couples were influenced to bear children by relatives and their communities. This result is supported by findings from a study conducted in Tanzania by Ezekiel, Leyna, Kakoko, and Mmbaga (2012). The study reported that childless couples were ridiculed and looked down upon in society. Ezekiel et al further found that people without children faced difficulties with social relationships as they were not considered real men and women. The study concluded that couples living with HIV faced problems living in communities with these attitudes.

The finding that HIV and AIDS information was experienced in social networks supports the argument for the benefits of social capital on health of individuals. Social capital "refers to features of social organisation, such as trust, norms, and networks that can improve efficiency of society by facilitating coordinated actions" (Putnam, Leonardi, and Nanetti, 1993, p. 167). Veenstra et al. (2005) found that the level of interpersonal trust and voluntary associations significantly associated with well-being.   Marks et al. (2011) suggest that certain aspects of social capital are more beneficial to the health of individuals than others. In particular Marks, Murray,

Evans, and Estacio posit that perceived trust and civic engagement are more health enhancing than local identity and local community facilities. However, this is contradicted by C Campbell, Williams, and Gilgen (2002) who found that although there was a positive association between social capital and health outcomes, it was too complex to make generalisations. On the other hand, the study identified some positive and negative social capital. Positive social capital was associated with belonging to sports clubs, youth clubs, and burial societies. Campbell, William, and Gilgen found that people who belonged to these social groups were less likely to be HIV positive or have casual sexual partners. Negative social capital was associated with local savings groups that hosted social functions with alcohol consumption. The study found that members of such social groups were more likely to engage in risky behaviours or be HIV positive. The results of the present study, especially where I have demonstrated the importance of lived others in the experience of HIV and AIDS information, support findings from other studies on the importance of social capital in behaviour change for people living with HIV. In their study Gregson et al. (2011) confirmed that participation in social groups resulted in adoption of safer sexual behaviours among women in Manicaland in Zimbabwe. The study suggests that the changes in behaviour were facilitated by high levels of social capital realised from participation in the social groups.

This finding also accords with my earlier discussion of homophily in section 9.2.1. As reported in chapter 5 most serodiscordant couples were influenced by HIV and AIDS information from informal-personal sources, some of which was wrong, despite having correct information from formal sources. This finding demonstrates the significance of positive social capital in information campaigns for people living with HIV in general, and specifically serodiscordant couples. Veinot (2009a) suggests that specific relationships with someone living with or affected by HIV is the major driver of knowledge and awareness of the pandemic. In demonstrating the significance of social networks in driving HIV and AIDS information for serodiscordant couples, my study raises some significant questions about the effectiveness of socially mediated HIV and AIDS information in behaviour change. A possible explanation is provided by Albright and Kawooya (2005b) who attributed the success of HIV and AIDS campaigns to the use of socially and culturally sensitive channels of communication in addition to the formal HIV and AIDS networks.

The findings of my study suggest that the differences in the experiencing HIV and AIDS information by the two partners are not as distinct and distinguishable from each other as one may assume from their different HIV statuses. I found that some HIV negative partners were even more anxious than their HIV positive spouses. As discussed in chapter 8 (section 8.3) the male partner in couple #19 was distressed with his wife's HIV positive result because he had a high risk perception of himself based on his sexual activity. In contrast, the HIV negative female

partner in couple #21 believed her test results, and her worry was the possibility of being infected by her spouse (see chapter 7, section 7.6.1.4). Another variation of experiencing HIV negativity was described by couple #17. Although their HIV test results were clinically different, the two partners were both anxious. Their description suggests that they experienced the HIV test results as a couple, not as individuals. Persson (2011) challenges the presumption that in serodiscordant couples the HIV negative status is experienced differently and in conflict with the HIV positive status. Persson argues that HIV negativity can be experienced in different ways depending on culture and contexts.

The findings of my study discussed in this section suggest that HIV and AIDS information had a social dimension. Most HIV and AIDS information was provided by lived others, in the communities and in health institutions. In addition, information was shared with lived others. When serodiscordant couples received HIV and AIDS information whose credibility was doubtful, they verified with health workers. Some couples found people with a problem similar to theirs and they were sources of experiential information. Experiences of living with HIV are identified as information in previous studies, for example, Minion (2010) identified this type of information among gay men living with HIV.

9.3.1   HIV and AIDS information, and myths

Throughout Chapter 6 and 7 I have discussed some myths relating to HIV and AIDS that were held by serodiscordant couples. Although HIV and AIDS awareness in Malawi is almost universal, the results of the present study suggest that some serodiscordant couples still believed that HIV could be transmitted by mosquitoes. Other studies have shown that although awareness of HIV and AIDS in most African countries is good, correct knowledge about the disease is still limited. Burgoyne and Drummond (2009) investigating the levels of correct awareness of the modes of transmission of HIV reported a wide variation between urban and rural, and between men and women. Similar to the results of the present study, Burgoyne and Drummond found one of common myths about HIV was that it could be transmitted by mosquitoes.

Another myth that was held by serodiscordant couples before diagnosis was the belief that if one's spouse is HIV positive then one is also positive. The results of this present study show that even after HIV test results were negative, HIV negative partners still believed they were positive. This resulted in serodiscordant couples engaging in unprotected sex despite their different HIV statuses. This study identified two other myths that affected the use of condoms among serodiscordant couples. Condoms were viewed as having holes through which the virus can

pass. Myths about condoms reported in the present study are similar to those found by other researchers.

Ngure et al. (2012) reported that male partners in serodiscordant relationships were reluctant to use condoms because they believed that condoms reduced sexual pleasure. In addition, misconceptions about serodiscordance also contributed towards inconsistent condom use among serodiscordant couples. Misconceptions reported in the study included HIV negative partners thinking that they were immune to HIV infection, and some believing that God will protect them. The findings of Ngure et al.'s study are consistent with those of the present study. As in Ngure et al.'s study serodiscordant couples in the present study were aware of the preventive strategies, and specifically condom use. However, most couples reported inconsistent condom use.

Another important myth from my study was the belief that if "*I reach orgasm faster than my wife I will not get infected*" (*HIV- Male partner, Couple #19*). A possible explanation of this myth is the male ego whereby men in society were expected to be strong. The male partner in couple #19 told me that men should teach their wives to always remember that they are women. To the best of my knowledge, this myth has not been reported elsewhere. Although it was only mentioned by one couple, it is an important issue that needs to be addressed by HIV and AIDS information for serodiscordant couples as it is similar to other myths reported in literature. As discussed earlier, Bunnell et al. (2005) observed that some health workers told serodiscordant couples that the one reason for their serodiscordance was because they had gentle sex. This suggests that some myths held by serodiscordant couples thrive on lack of correct and relevant HIV and AIDS information.

The results of this present study indicate that myths undermined the intended outcomes of HIV and AIDS information provided to serodiscordant couples in VCT sessions. This element of the findings of the present study is consistent with Kang'ethe and Xabendlini (2014) observation that myths, misinformation, and misconceptions distract people from the truth and derail HIV prevention programmes. Kang'ethe & Xabendlini further recommends that patients should always be advised to seek therapies that have scientific basis in order to avoid myths. Similarly, Mufune (2005) reported that although people in Namibia were aware of AIDS and that condoms are the best prevention method from sexual transmission of HIV, they still believed some myths about HIV and AIDS, and condoms.

Another important finding of my study is the intersection of culture, religion and myths about HIV. Evidence from my study suggests that some faith based organisations used myths to discourage their followers from using condoms. Similarly, cultural values that encouraged women to respect

their husbands made them vulnerable to HIV as they were not able to negotiate safe sex. My findings are consistent with those from a study by Tobias (2001). Tobias found that some people in Swaziland believed that only God can protect them from HIV infection and that condoms are infected with the HIV virus. The finding of my study, taken together with results from previous studies suggests that information services need to be harmonised across all sectors of society. In addition, it confirms the polarised views about HIV prevention strategies (Joint United Nations Programme on HIV/AIDS, 2009). However, for serodiscordant couples, it casts doubt on the effectiveness of HIV and AIDS information provided by faith-based organisation in isolation from other national and international agencies.

The findings of my study and the discussion in this section suggest that myths were mostly perpetuated through peer-to-peer casual talk. At the same time, it is evident that myths thrived on ignorance of the correct facts about serodiscordance, and HIV and AIDS. This confirms Chatman's (1999) description of life in a small world where people are concerned with what is local and near. Like in Chatman's small world, serodiscordant couples appeared to be more influenced by HIV and AIDS information that was local. It is evident that when one partner was ill most serodiscordant couples looked for information from within their small world. Only when that information was not working did they look from outside their small world. Consistent with observations made by Chatman (1996) that people inside a small world do not trust those from outside as sources of information, serodiscordant couples in my study did not consider HIV negative people as trusted sources of HIV and AIDS information. These findings draw attention to the question of effective means of making available correct and up-to-date HIV and AIDS information at the local level, and shape everyday talk in order to counter myths.

Although previous studies have categorised the issues raised by couples about condoms as myths, interpretation of my findings suggest that these issues are significant and need to be addressed. When commenting on the manner in which they were told about their HIV test results, serodiscordant couples said that they were frustrated by the lack of opportunities to ask questions. Those remarks could also be relevant in cases where serodiscordant couples have issues with some HIV preventive approaches such as condoms. Based on the findings of my study, I argue that HIV and AIDS information needs to acknowledge and address the issues raised by couples before presenting the benefits that outweigh the issues. An example is where some partners were reluctant to use condoms because they reduce sexual pleasure.

9.3.2   (African) Religion, beliefs and conception of illness

Sub-Saharan Africa has been described as of the most religious regions in the world with the fastest growing religious population (Pew Research Center, 2012). In addition, the region has also many thriving traditional religions and belief systems.

One of the central concepts in phenomenology, intentionality, states that consciousness is consciousness of something (D. Allen, 2005). Since consciousness of all things is through the five senses, there are arguments that therefore people cannot experience God because He is "not an object in space and time" (Vardy, 2005, p. 86). However, in religious experience human beings transcendent the limitations of the five sense and experience a supernatural being, God. Thus religious language uses symbols, metaphors, analogies and parables (D. Allen, 2005). Hyde (2008) contends that people have always searched for an absolute Other in their quest to find purpose and meaning in life. Yet Van Manen (1997) and Hyde (2008) posit that when we encounter lived others, we do so in bodily form. Similarly, Vardy (2005, p. 86) contends that God is "not an object in space and time". This is supported by Moran's (2000) discussion of Emmanuel Levinas' phenomenology. According to Moran, Levinas contended that God should be viewed as "other than the other" (p. 331). In addition, Turner and Turrell (2007) observes that Levinas' God is separated from human beings and resists manifesting in the material world. Following from the preceding remarks and empirical evidence presented in chapter 5 there are enough grounds for positing that God is absolute and different from lived others.

In many African belief systems the 'other' is extended to the living dead. However, most African cultures distinguish the social or natural world and the spirit world. These two worlds are parallel and they influence each other (Cox, 2014). According to Koenane (2014) most African cultures believe that the inhabitants of the spirit world, the living dead, have powers to cause illness. Therefore, when illness comes people consider negative intervention of the living dead as a possible cause. Some serodiscordant couples in my study went to traditional doctors before going to the hospital. This was based on the belief that the HIV infection was as a result of the intervention of the spirit world. The implication is that HIV and AIDS information was ignored.

My study draws attention to the importance of HIV and AIDS information provided by faith based organisations. Considering the hopelessness of HIV infection arising from the absence of a cure, religion plays an important role in restoring hope among people living with HIV in Malawi. A possible explanation of this finding is that in their life-world serodiscordant couples were unable to find meaningful support from the tangible things and lived others. As a result, they find hope in their relationship with the invisible God, the lived supernatural. The results of this study suggest

that some serodiscordant couples were encouraged by reading the holy books of their religion. The role of religion in coping with HIV and AIDS was also investigated by Hodge and Roby (2010) in Uganda. The findings of my study showed that belief in God, prayer and singing spiritual songs were the second most important coping strategy after attendance to HIV and AIDS support groups for women living with HIV. Although God and ancestral spirits were not encountered in bodily form, they were nevertheless experienced in a real way.

A less positive experience with faith based organisation was HIV and AIDS information which discouraged the use of condoms. As stated earlier, most serodiscordant couples were religious and derived hope from their belief in God and prayer. In addition, the results of this study indicate that some serodiscordant couples believed that the solution for their illness was in heaven. However, based on proof of use many serodiscordant couples indicated that condoms were the important means for preventing HIV transmission to the HIV negative partner. Therefore, HIV and AIDS information that advised serodiscordant couples to use condoms was experienced with guilt of sin since it was against the teachings of their religions.

9.3.3   Culture and experiencing HIV and AIDS information

Some important findings in this study were on the cultural aspects of experiencing HIV and AIDS information. Marriage is a cultural institution. In Malawi some cultures require men to pay bride price when marrying. Although only one female HIV positive partner in this present study linked bride price and the circumstances that led to her HIV positive status, evidence from previous studies indicated that this is a significant determinant of the dynamics of marriages in Africa. Heeren, Jemmott III, Tyler, Tshabe, and Ngwane (2011) reported that paying bride price contributed to the legitimacy of marriages and that it did not contribute to the sexual behaviour of the husband. However, in their study the Malawi Human Rights Commission (2006) found that although many respondents talked in favour of bride price, some, especially women considered it as a form of buying. In addition, women thought because of bride price women were viewed as breeding machines. The study also found that bride price bonded the two partners and as a result women were forced to remain in abusive relationships. In this present study, one HIV positive partner who had separated from her husband believed that the bride price paid by her husband made her part of his family. Even after her husband married another woman she considered herself bound by the bride price. This in turn made her unable to act on HIV and AIDS information. As presented in the results chapters, the woman felt she was bought and that the husband could do anything with her.

Before diagnosis of the HIV infection some serodiscordant couples had ways of explaining the illness which were culturally biased. This also accords with earlier observations in Chapter 7, which showed that some serodiscordant couples went to traditional doctors before going to the hospital. One couple said that they believed that the illness of the male partner was as a result of ancestral spirits wanting to give him prophetic powers. This demonstrates that HIV and AIDS information was experienced alongside cultural explanations of illnesses. Kalichman and Simbayi (2004) confirms these traditional beliefs about the causes of HIV in a study conducted in South Africa. In the study one in three people either believed that HIV is caused by spirits and supernatural forces or were not sure. The results also showed that people who believed that HIV is caused by spirits and supernatural forces were more likely to have incorrect general knowledge of HIV.

In the absence of culturally appropriate terminologies for HIV and AIDS messages, serodiscordant couples in my study appeared to be using figurative language and proverbs. Dei (2015) observes that in African cultures proverbs are part of pedagogical tools for teaching young people about values, promoting character building, and giving advice. However, Kamanga (2014) contends that figurative language and idioms used in Chichewa, have literal and idiomatic meanings and are not always understood by children. Considering that the idioms, figurative language and proverbs are context specific, I would also argue that even adults not familiar with the context, may not understand the meaning. Therefore, if used in HIV and AIDS information these local idioms, proverbs and figurative language may be understood differently by different people depending on their familiarity with the context.

9.3.4   Gender and experiencing HIV and AIDS information

In this present study, gender came up as one of the important themes in the experience of HIV and AIDS for serodiscordant couples. Malawi has a gender inequality index of 0.591 (United Nations Development Programme (UNDP), 2014). UNDP defines gender inequality index as "a composite measure reflecting inequality in achievement between women and men in three dimensions: reproductive health, empowerment and the labour market." An index of 0.591 suggests the existence of large inequalities between men and women in Malawi.   In Malawi HIV testing is mandatory for pregnant women (Kavinya, 2014). Against this background some serodiscordant couples in this present study claimed that it was easier for women to go for HIV testing than their male counterparts. Skovdal et al.'s (2011) study also found that men can shun or delay HIV testing because HIV positive status threatens the socially constructed notion of masculinity.

The findings of this study suggest that HIV infection of one partner made the home, as a lived space, to be no longer safe. To make the home safe, the HIV positive partner was in many cases sent away. Interestingly, results of this study indicate that female partners were more likely to be sent away than male partners. Further, female partners who stayed in the home with their spouses or returned were forced to disregard HIV and AIDS information that was provided by health workers and engage in unprotected sex. According to World Health Organisation (2015a), in Sub-Saharan Africa, women account for 60% of all people living with HIV. Unfortunately, evidence from this present study indicates that women in serodiscordant relationships, regardless of their HIV status, were prevented from acting on HIV and AIDS information by their spouses. As stated earlier in this section, this included being forced not to use condoms.

These findings are corroborated by others studies conducted in Malawi. Ghosh and Kalipeni (2005) reported that due to their vulnerable positions, women in Malawi were not able to raise issues about HIV and AIDS with their husbands. The majority of women interviewed in Gosh and Kalipeni's study indicated that it was not acceptable for them to use condoms with their spouses in order to protect themselves from HIV. Gosh and Kalipeni's findings are consistent with the results of this present study which indicated that women were forced by their spouses not to act on HIV and AIDS information by not using condoms. Findings of my study suggest that the actions of partners who prevented their spouses from acting on HIV and AIDS information were due to ignorance of the truths about HIV and serodiscordance.

9.4   Chapter conclusion

The third research question in this present study was: how do serodiscordant couples make sense of HIV and AIDS information? The discussion in this chapter identifies religion, culture and gender as important mediators of HIV and AIDS information for serodiscordant couples. The discussion suggests that HIV and AIDS information was assessed as being religiously or culturally correct or not. In addition, gender roles appeared to play a part in the making sense of HIV and AIDS information. Specifically, the findings discussed in this chapter suggest that female partners were prevented from acting on HIV and AIDS information by their spouses.

The findings of the present study discussed in this chapter highlights the many ways in which HIV negative partners experienced HIV and AIDS information. In many cases HIV negativity is viewed as the opposite of and in confrontation with HIV positivity. However, findings of my study suggest that there were different variations of experiencing HIV negativity in serodiscordant couples. Some HIV negative partners made effort to access support and manage the serodiscordance together with their spouses. Some who did not have correct HIV and AIDS information about

serodiscordance blamed their spouses for the HIV infection. Other HIV negative partners believed that they too were infected because HIV is sexually transmitted.

Chapter 10

Conclusion

10.1   Introduction

The main aim of this thesis has been to investigate the experiencing of HIV and AIDS information by serodiscordant couples in Malawi. This topic was important because HIV is the major cause of death across the spectrum of the population in Malawi (Malawi Government, 2011). Economically, HIV has an impact on Malawi as it affects productivity. In a country that is dependent on agriculture, HIV and AIDS have affected agriculture and food security through loss of labour (Arrehag, de Vylder, Durevall, and Sjöblom, 2006).

In this concluding chapter, I will present a summary of the findings in the context of the study's research questions and objectives. Then I will discuss limitations of the study. In light of the findings, I will discuss the contributions of my study to knowledge, theory, methods and practice. I will also discuss contributions to national development and to the lives of the serodiscordant couples. In the final part of the chapter, I will make recommendations for practice and future research.

10.2   Revisiting research questions

The present study set out to answer the following main research question: How do serodiscordant couples experience HIV and AIDS information in Malawi?

In order to answer the main research question the following sub-questions were pursued:

1.   What HIV and AIDS information do serodiscordant couples in Malawi need?
2.   From what sources do serodiscordant couples get HIV and AIDS information?
3.   How do serodiscordant couples make sense of HIV and AIDS information?
4.   How has the experience of discordance affected the couples' information world?

This study used a phenomenological approach to investigate the experiencing of serodiscordant couples in Malawi. Specifically, Max Van Manen's approach was used. Van Manen's approach has six research activities, and these are: turning to the nature of lived experience, investigating lived experience as we live it, reflecting on essential themes, phenomenological writing, maintaining a strong and oriented relation to the phenomenon, and balancing the research context by considering parts and whole.

Data were collected using in-depth interviews. After each interview I asked the couple to show me information objects they had in their possession. I photographed the information objects in order to keep a record.

RQ 1: What HIV and AIDS information do serodiscordant couples in Malawi need?

My study found that HIV and AIDS information on serodiscordance was not available to many couples. Where it was available serodiscordant couples thought it was inadequate or superficial. Most serodiscordant couples said they had needs arising from serodiscordance. In order to meet these needs they needed HIV and AIDS information.

In chapter 6 I presented the serodiscordant couples' needs that triggered information needs. These are the need for physical health, biomedical needs, the need to manage serodiscordance and prognosis of HIV infection, the need for emotional and social support, the desire to bear children, and financial needs.

RQ 2: From what sources do serodiscordant couples get HIV and AIDS information?

Serodiscordant couples were asked to name the sources they used to obtain HIV and AIDS information. As presented in table 6.1 (Chapter 6), I categorised information sources that are used by serodiscordant couples in four groups. The first category was personal-formal sources, the second category was personal-informal sources, the third category was impersonal-formal sources, and the fourth category was impersonal-informal sources. Serodiscordant couples were found to be using their and others' bodies as sources of HIV and AIDS information. Further, music was identified as an important source of information.

The findings of my study suggest that some places that contained information sources were not welcoming to HIV negative partners. In most cases, HIV positive status was considered as the default qualifier for membership to such groups and therefore HIV negative partners did not qualify.

RQ 3: How do serodiscordant couples make sense of HIV and AIDS information?

Findings of my study suggest that serodiscordant couples evaluated HIV and AIDS information for cultural, religious, and moral relevance. As presented in the framework for experiencing HIV and AIDS information (see Chapter 8, Figure 8.4) couples filtered information that was found to be irrelevant. However, in some cases, information was filtered as a strategy to cope with too much information.

HIV and AIDS information was also viewed as being accessible or inaccessible. Accessibility was described in terms of language, format and location. For instance, couples or partners who could not competently read or write in the English language described information in that language as being inaccessible. Similarly, illiterate couples or partners found information in print to be inaccessible.

RQ 4: How has the experience of discordance affected the couples' information world?

Serodiscordant couples were asked if they were actively seeking HIV and AIDS information before one partner was diagnosed. Most couples reported that both partners were indifferent towards HIV and AIDS information before diagnosis of one partner. My study also found that some HIV negative partners continued to be indifferent towards HIV and AIDS information after the diagnosis of their partner as they considered information irrelevant to their negative HIV status.

Before diagnosis of one partner, most serodiscordant couples thought HIV and AIDS information was for HIV positive people, and for people who are promiscuous and sex workers. In addition, some couples experienced HIV and AIDS information as being too explicit and obscene before diagnosis of one partner. However, most couples changed their attitude towards HIV and AIDS information after diagnosis.

Main Research Question: How do serodiscordant couples experience HIV and AIDS information?

The four research questions presented above were collectively aimed at exploring dimensions of the main research question. I will now discuss how the main research question has been answered. HIV and AIDS information was experienced in the life-world. Within their life-worlds, serodiscordant couples were found to inhabit different small-worlds such as the home, hospital, and HIV and AIDS support groups. In these small-worlds, HIV and AIDS information was described as being available or unavailable. Where information was available, it was also described as being accessible or inaccessible.

The participants' experience of HIV and AIDS information was captured in the framework presented in figure 8.4. The framework proposes that information was experienced at four stages. HIV and AIDS information was experienced while anticipating it. As described in chapter 8 anticipating HIV and AIDS information was emotional. In addition, serodiscordant couples started evaluating the information they were anticipating for cultural, religious and moral relevance.

HIV and AIDS information was also experienced while interacting with it. The interaction was physical in case of items such as books and leaflets, or non-physical for information such as radio broadcasts. Some HIV and AIDS information was experienced with positive emotions such as that which explained how to prevent transmission of HIV to an unborn baby. Other information was experienced with negative emotions, especially that which described negative outcomes of HIV infection. My study also identified some partners who experienced HIV and AIDS information with emotions that were considered ambiguous. In the absence of vaccine and cure for HIV, information was experienced with uncertainty and despondency as the likely outcome mostly described by HIV and AIDS information was death.

After interacting with HIV and AIDS information, the next stage was to act on it. In this stage partners in serodiscordant couples performed meaningful actions based on the information they had. In this stage HIV and AIDS information was experienced with emotions similar to those described in the previous stage (Interacting with information).

In all stages described this far, serodiscordant couples were reflecting on HIV and AIDS information. HIV positive partners reflected on HIV and AIDS information for is effectiveness in managing their illness and preventing transmission to their partner. On the other hand, HIV negative partners reflected on HIV and AIDS information cognisant of the risks of living with an HIV positive spouse.

Although, clinically, the two partners' HIV statuses were clearly differentiated as positive and negative, their information experiencing was not equally distinct. In addition, the findings of my study suggest that some serodiscordant couples experienced HIV and AIDS information with denial, especially soon after diagnosis.

10.2.1 The research objectives

In this section I will discuss how, by answering the research questions, I have achieved the aim and objectives of my study. The aim of the study was to describe and interpret how serodiscordant couples in Malawi experience HIV and AIDS information. To achieve this aim, the following specific objectives were pursued:

1. Review previous research on information behaviour of HIV positive people and serodiscordant couples in particular
2. To identify information needs of serodiscordant couples in Malawi
3. To describe sources of HIV and AIDS information available to people serodiscordant couples in Malawi

4. To describe how serodiscordant couples' experience of HIV and AIDS information has changed since their or spouse's serostatus changed

5. To describe how serodiscordant couples make sense of HIV and AIDS information

6. To make recommendations for changes in the approaches to HIV and AIDS communication

Objective 1: Review previous research on information behaviour of HIV positive people and serodiscordant couples in particular.

Literature on information behavior of people living with HIV was reviewed as presented in chapter 2. Throughout this project, I kept up-to-date by, among other things, subscribing to table of contents alerts of major journals on information behavior, and HIV and AIDS.

Objective 2: To identify information needs of serodiscordant couples in Malawi.

In chapter 6 I presented needs serodiscordant couples had because of the serodiscordance. In addition, I demonstrated that the needs serodiscordant couples had triggered information needs.

Objective 3: To describe sources of HIV and AIDS information available to people serodiscordant couples in Malawi.

My study has identified information sources serodiscordant couples use to access HIV and AIDS information. The sources are presented in chapter 6 where I have categorised as personal-formal, personal-informal, impersonal-formal, and impersonal-informal. Drawing on the life-world as the contextual framework of experiencing HIV and AIDS information (presented in chapter 5), I presented an interpretation of the information sources in chapter 8. I discussed the five existentials of the life-world as sources of HIV and AIDS information for serodiscordant couples.

Objective 4: To describe how serodiscordant couples' experience of HIV and AIDS information has changed since their or spouse's serostatus changed.

I asked serodiscordant couples to describe how they experienced HIV and AIDS information before one partner was diagnosed (see sections 6.10, 6.11, 7.6.1.2, 7.8 and 8.2.1). The general finding of my study was that HIV and AIDS information was considered to be for sex workers and people in casual sexual relationships. I have described how HIV and AIDS information was experienced with indifference because the couples considered their HIV risk levels to be very low.

Objective 5: To describe how serodiscordant couples make sense of HIV and AIDS information.

In chapter 7 I used illuminations from the life-world of the serodiscordant couples presented in chapter 5 to describe how they made sense of HIV and AIDS information. Findings of my study suggest that serodiscordant couples used religious, moral and cultural lenses to understand HIV and AIDS information. For example in section 7.10 I described how socially defined gender roles influenced the two partners to understand HIV and AIDS information in a particular way.

Objective 6: To make recommendations for changes in the approaches to HIV and AIDS communication.

Using insights from my findings I have made recommendations for practice, policy and further research in section 10.4 in this present chapter.

Research aim: To describe and interpret how serodiscordant couples in Malawi experience HIV and AIDS information.

As presented in chapter 1 (section 1.4), the description referred to in the research aim and objectives has three dimensions. These are description of **what** happened, **how** it happened and **why** it happened. I have used words of serodiscordant couples to present experiencing of HIV and AIDS information in chapter 7 (the '**what**'). In chapter 5, I described the life-world as the context in which information experience took place. Then in chapter 6 I presented the needs serodiscordant couples had that triggered information needs (the '**why**'). Using the life-world as the context, I presented a theoretical framework of experiencing HIV and AIDS information in chapter 8. Thus chapter 8 describes **how** information experience took place. In chapter 9 I draw on other studies to discuss **why** serodiscordant couples experienced HIV and AIDS information in the manner they did.

10.3   Limitations of the study

The approach used to interview serodiscordant couples had some limitations. I had two options: to interview the two partners together or to interview them separately. Both approaches had advantages and disadvantages. I chose to interview both partners together because this option addressed most of the ethical problems that affect interviewing couples. In addition, logistically it was the most practical option considering that most couples were only able to commit about 90 minutes of their time to the interviews.

Interviewing two partners in a serodiscordant couple had some limitations. Some partners were not free enough in the presence of their spouses to discuss issues they considered private to their lives. Throughout the study, I ensured that this limitation did not compromise the findings. A sample of 45 participants (21 couples and 3 individuals) ensured that different voices were

represented in the data I collected and that I had a good number of couples that were open and free to discuss their experiences. Further, interviewing the three individuals who had separated from their partners provided an opportunity to explore HIV and AIDS information experience with them away from their spouses.

The other limitation concerns interviewing in the local language and translating into English. The issues associated with translation of interview data in qualitative research are discussed in chapter 3 (section 3.7.1.2). In the present study, translating data from Chichewa to English had the likelihood of losing the meaning of serodiscordant couples' descriptions. In order to minimise the impact of translation on the integrity of my findings I stayed with the data in the local language for as long as I could. The data were analysed in the local language, and I only translated the quotations that were used in writing up the results. In addition, all translations were validated by a language expert for the University of Malawi, Centre for Language Studies. Furthermore, I used the English/Chichewa dictionary and a friend, Dr Bright Molande to come up with terms in English that were correct representation of the Chichewa concepts that came out in the analysis.

10.3.1   Contribution to theory

- **Contribution beyond the discipline of Library and Information Science (LIS)**

One of the major contributions of this study to theory concerns the life-world in general, and specifically the identification of the fifth existential. The concept of life-world proposed by Van Manen (1997) has four existentials: lived body, lived others, lived space, and lived time. The present study identified moral and religious values as one of the major themes in experiencing HIV and AIDS information. As discussed in chapters 8 and 9, God and ancestral spirits as experienced by serodiscordant couples was a dominant life-world existential, distinguishable from the four proposed by Max Van Manen. Thus, the present study proposes a fifth life-world existential as presented in section 8.2.5 and Figure 8.2. The findings of my study pose a fundamental question about the universal applicability of Max Van Manen's four life world existentials across cultures.

The life-world of serodiscordant couples in Malawi has a significant dimension which concerns practice of religion and consultation with ancestral spirits. Van Manen (1997) briefly mentions God as the absolute Other. However, as discussed in chapter 9, God and ancestral spirits can be differentiated from lived others hence the fifth life-world existential being proposed.

Considering that Van Manen's approach was developed in the field of education, and that it has been applied in other fields such as nursing and medicine, this contribution to theory goes beyond LIS field.

- **Contribution to the development of information behaviour research domain**

The second area of contribution is in the reinforcement of information experience as a research domain, through contribution of new insights and a framework. Information experience is an emerging concept in information science research. "It has only become a concept of discourse in information research literature within the last several years" (Partridge and Yates, 2014, pp. 21-22). Therefore, the present study contributes to the body of this emerging research domain in two major ways. First, the study brings to fore the concept of information experience in information science research and demonstrates its importance as a research domain.

The present study has demonstrated that information experience is a viable field of research within information behaviour research. In addition, my study has raised the visibility of information experience to researchers and practitioners.

Although there are many studies that have investigated serodiscordant couples, to the best of my knowledge there in no study that investigated information behaviour of this group. In addition, there are no known studies on information behaviour or information experience conducted in Malawi. My study contributes to the body of literature on information experience and information behaviour of a specific group of people living with HIV. This study has contributed towards the understanding of the experiencing of HIV and AIDS information. While this present study is on serodiscordant couples, the results some of the findings contribute to the understanding of information experience of couples in general.

The present study has investigated how serodiscordant couples experience HIV and AIDS information. In general this study extends the existing body of research as there appears to be limited research in the area of information experience.

My study also extends the body of knowledge involving intersubjectivity in the experience of HIV and AIDS information. As stated earlier, the life-world was identified as the overarching context of experiencing HIV and AIDS information. Thus, serodiscordant couples inhabited lived spaces with other people. The findings of this present study suggest that HIV and AIDS information was experienced with and through others.

- **Contribution of a conceptual framework of experiencing information and a definition of information**

My study makes four contributions to theory within the discipline of LIS. First, my study has described and articulated the life-world as the context of experiencing information. While most information behaviour research just mentions 'context' as an important aspect of information behaviour, my study has contributed to the understanding of the context by describing the five existential of the life-world. By using Elfreda Chatman's Theory of Life in the Round I have described the context in even a greater detail.

The second contribution to the body of knowledge from the present study is the theoretical framework for experiencing HIV and AIDS information presented in chapter 8. As stated earlier, information experience is a new research domain. In addition, to the best of my knowledge, there are no known theories or models of information experience. Therefore, the theoretical framework of experiencing HIV and AIDS information developed in this study contributes to the theorising and modelling of information experience.

Thirdly, my study makes a contribution to knowledge by providing a definition of information which encapsulates the richness of information experience. The definition I have provided (page 217) captures the complexity of HIV and AIDS information as experienced by serodiscordant couples. Defining information as **stimuli, heard, seen, tasted, and felt, that played a role in formation of perceptions, beliefs, and attitudes about HIV and AIDS** suggests that simple activities such as providing a book may not be adequate response to information needs. The definition of information contributed by my study is significant, as it can assist health information service providers to broaden their focus of what constitutes information.

The fourth contribution made by my study is the categorisation of sources of information (table 6.1). Based on the findings of my study I came up with a categorisation that uses two attributes of the information sources. These are: whether the source communicates information directly to an individual or communicates using a group based approach (personal or impersonal); and, whether the information sources are constituted in some regularised manner or not (formal or informal). The four categories of information sources I identified are clearly defined and can be used by other researchers to categorise information sources.

10.3.2 Methodological contributions

Hughes (2014) suggests that research approaches most suited for the study of information experience are ethnography, phenomenography, case study, action research, grounded theory,

and ethnomethodology. My study extends the body of literature in that it has established that phenomenology is also a viable approach for studying information experience. I used phenomenological interviews to invite serodiscordant couples to describe how they experience HIV and AIDS information. In addition, phenomenological analysis was useful in arriving at rich descriptions of HIV and AIDS information experience.

As presented in section 10.3.1, my study has contributed to theory by identifying the life-world as the overarching context of experiencing HIV and AIDS information, and spirituality as the fifth existential of the life-world. From a methodological point of view, identification of the life-world, with the fifth existential, as the context of experiencing information, contributes to our view of the social world. As stated by Van Manen (1997), the structures of the life-world guide reflection, and I will add interpretation, into the research process. Therefore, my findings add to this tool-set by identifying a fifth existential of the life-world.

10.3.3   Contributions to practice

My study found that there was diversity in the information needs of serodiscordant couples. In addition, the study found there were many factors that enabled or prevented serodiscordant couples from accessing HIV and AIDS information. From these diverse, but interplaying, factors one would argue that there could be no 'one size fits all' approach to HIV and AIDS information provision in general, and specifically for serodiscordant couples. In addition, my study's findings support criticisms of the use of mass-media for transmitting HIV and AIDS information. Yoder, Hornik, and Chirwa (1996) evaluated claims that listening to a radio drama on HIV and AIDS had positive behavioural outcomes in Zambia and found that the changes could not be linked to listening to the radio drama. The success of mass-media in HIV and AIDS information campaigns has also been questioned by Albright (2007) and Airhihenbuwa and Obregon (2000).

My study thus contributes towards the understanding of the information experience of specific groups of people living with HIV, in this case serodiscordant couples. This can lead to improvements in practice as discussed in the recommendations section (section 10.4.1). Results of my study provide insight into the significance of the five life-world existentials in mediating a positive experience of HIV and AIDS information. The lived-body of an individual is influenced by lived others in the experiencing of HIV and AIDS information. In addition, culture, social norms, and social expectations that form a localised world-view, influence people to experience HIV and AIDS information in certain ways. This localised world-view plays out in lived spaces that are occupied by individuals (as lived body) and where they interact with lived others. As discussed in chapter 5, some lived spaces play a spiritual or religious function. Since HIV infection was viewed

as a hopeless situation, most serodiscordant couples turned to religion for a sense purpose or to seek explanations of their illnesses from ancestral spirits.

The findings of my study also extend knowledge of practice in the area of design of HIV and AIDS information. Findings from my study suggest that HIV and AIDS information in Malawi is designed by health experts and passed on to the users. This top-down approach instils a sense of exclusion in some serodiscordant couples. As discussed in chapter 9 in Malawi there are no health information standards that could be used to regulate the design and provision of HIV and AIDS information. In the United Kingdom, information standards ensure that the consumers of health information are involved in the design process where information is piloted with them before it is finalised (Department for Health, 2010).

10.3.4   Contribution to Malawi context

The present study found that libraries and the internet are not used as sources of HIV and AIDS information in Malawi. Therefore, my study identifies the absence of one important sector on the HIV and AIDS information landscape.

Malawi's performance on the millennium development goals that are expiring in 2015 was not impressive. I would argue that part of the problem that contributed to the poor performance was inability of citizens to access, process, understand, and utilise information in different sectors of their society. Therefore, attainment of the new Sustainable Development Goals, especially goal 16.10 which include access to information (United Nations, 2015), will depend on understanding of information experience of people. Findings of my study contribute to the understanding of how people experience information. The approach I have used to gather descriptions of how serodiscordant couples experience HIV and AIDS *information*, and the analysis I have conducted, have the potential to be applied in other sectors. First, the approach and analysis can be applied to the health sector in general to understand how people experience health information. Secondly, these can be applied to experiencing of information in other sectors such as education, agriculture, climate change, and environmental management. Based on insights from conducting this research, I posit that understanding how people experience information is essential to achieving global and country level development goals.

10.3.5   Contribution to the lives of serodiscordant couples

Sentiments expressed by serodiscordant couples after being interviewed suggest that participation in the study had an impact on their lives. First, serodiscordant couples expressed gratitude for my visit to their homes. As indicated in chapter 6, serodiscordant couples preferred HIV counsellors to visit them in their homes and discuss about HIV and AIDS. Although my visits

were for research purposes, the couples viewed them differently. The visits had an information value for the couples and were viewed as a form of support.

Serodiscordant couples like other people living with HIV are marginalised and stigmatised. In addition, there are not many fora for them to speak about their experiences. My study provided one such forum. As discussed in chapter 4, one HIV positive partner requested to be identified and not be anonymous. This suggests that she viewed the research interview as an opportunity to tell her story.

10.4   Recommendations

I recognize that my study findings have some practical and policy implications on the design and provision of HIV and AIDS information. Based on the findings of this present study I posit a number of recommendations for practitioners, policy makers.

10.4.1 Recommendations for practice

In view of the complex interaction of the five existentials of the life-world presented here, I would argue for a cascading approach to HIV and AIDS information provision. I will use communication strategies proposed by Mchombu, Bruton, Cocks, and Evans (2002) to illustrate this recommendation. Mchombu et al. proposed the use of radio and cassette listening clubs. In a cascaded approach, I am proposing that the radio and cassettes will be part of a package. HIV and AIDS information should be targeted at specific groups of people such as serodiscordant couples. Delivery of information would then be done in steps. The first step would be at group level. At this level people would listen to the radio or cassette, or watch some video and discuss the contents. The discussion would draw some action plan to be followed through by couples or individuals. The information package would contain information objects such as booklets, brochures or leaflets that individuals can take home.

The other recommendation I would make based on the findings of my study is the introduction of standardized HIV and AIDS information packages for special groups. To the best of my knowledge, HIV and AIDS counsellors in Malawi do not have standard information materials they can use or give out to special groups such as couples. I recommend that the information packages should be in different format to suit information needs of different people. "In order to reach the 2015 global AIDS targets, getting the right information to the right people at the right time is necessary" (Joint United Nations Programme on HIV/AIDS, 2014, p. 287). The experiencing of HIV and AIDS information I have described suggests that information services are designed with little or no regard for the needs of the target audience. Hepworth et al. (2014, p. 1045) argue that users of information services are "experts of their reality", and they should be

considered "partners" when designing the services. Therefore I further recommend a participatory approach to the design of the information packages.

As discussed in chapter 9 libraries and internet were not identified as sources of HIV and AIDS information by the serodiscordant couples. Although there could be other reasons for this result it suggests these potential sources of HIV and AIDS information are not used to take information to target audiences. I therefore suggest a review of services provided by public and health libraries in Malawi with the aim of introducing services that can benefit the general population.

10.4.2   Recommendations for policy makers

Findings from my study suggest that serodiscordant couples preferred HIV and AIDS information to be disseminated to them by health workers visiting their homes. The preference for home visits reveals the cultural undertones in the experience of HIV and AIDS information by serodiscordant couples. For couples, home is a safe place where, culturally, the relationship between husband and wife thrives. Besides, in Malawi counselling for newlyweds is a private and secluded activity held behind closed doors. In addition, marital problems are discussed and resolved in the house by marriage mediators. Therefore, I would recommend that information services for married couples should comply with traditional norms and practices that dignify marriage. In addition, I would recommend special HIV and AIDS information materials for marriage counsellors to enlighten them about HIV and serodiscordance.

Findings of the present study suggest that lack of standards for HIV and AIDS information contributes to negative experiencing of the information. Therefore I posit that in order to ensure positive experience of HIV and AIDS information there is need for introduction of information standards. In addition, organisations that produce health information should be subject to accreditation.

Considering that not all organisations or people that produce HIV and AIDS information in Malawi are health professionals, I would recommend a training programme for this group. The training should orient producers of HIV and AIDS information to the psychological, sociological, religious and cultural effects of the information they produce. Organisations would also be acquainted with information standards proposed earlier in this section.

10.4.3   Recommendations for further research

The present study has touched on many important issues that could not be investigated within the scope of this study. In this section I will make recommendations for further research based on insights from my study.

This study investigated the experience of HIV and AIDS information by serodiscordant couples in Malawi. However, there other groups of people who are left out of HIV and AIDS programmes in Malawi such as men who have sex with men, women who have sex with women, and people who inject drugs. Since homosexuality and drug use are illegal in Malawi, the people involved do such things in secret. Therefore, these groups are worth investigating so that their HIV and AIDS information experience is understood.

Another area for further research concerns information standards. This present study has found that HIV and AIDS information is experienced as lacking standards. However, there is need for further research to develop the information standard based on the criteria people living with HIV use to evaluate HIV and AIDS information. Another study would then investigate if the introduction of information standards has a positive effect on the experiencing of HIV and AIDS information.

One of the findings of my study was the criticism by serodiscordant couples that HIV and AIDS information materials are usually implemented without being trialled. Based on this finding I would recommend further research to trial HIV and AIDS information materials that are used for counselling couples. Following on my recommendation for introduction of standardised HIV and AIDS information packages or kits for special groups such as couples, I would also recommend trialling the new information kits.

Finally, I will recommend further research to test how useful the conceptual framework I have proposed in chapter 8 would be in the design of HIV and AIDS information materials and campaigns. The testing will also validate the aspects of my conceptual framework in real life information experience scenarios.

10.5   Concluding remarks

"If people cannot obtain, process, and understand basic health information, they will not be able to look after themselves well or make good decisions on health. Health literacy is not just about ensuring that patients can read and understand health information, it is also about empowerment." (Coulter and Ellins, 2007, pp. 24-25). In agreement with Coulter and Ellins, I posit that if serodiscordant are not able to "obtain, process, and understand" HIV and AIDS information they will not be able to manage their serodiscordance (pp.25).

In this thesis, I have demonstrated that the life-world is the overarching framework of experiencing HIV and AIDS information. In doing so, I have shown that HIV and AIDS information experience is socially situated. Therefore, information coming into the life-world is subject to

scrutiny and evaluation. Based on Chatman's (1991) conception of the small-world, information coming from outside is treated with suspicion. It therefore follows that HIV and AIDS information that is not deemed socially, religiously, or culturally appropriate would be treated with suspicion by serodiscordant couples. I hope that recommendations made in this chapter can address the problems of lack of trust.

It is fitting to dedicate the final words of my thesis to the serodiscordant couples that participated in my study. Insights from my study suggest that living with serodiscordance can be a daunting experience. This can be exacerbated by lack of HIV and AIDS information. The male HIV negative partner in couple #17 said: *"information for people like us, it is very few. Information is very few so many people don't believe that one partner can be positive and the other negative".* When HIV and AIDS information is available it is not in the format they prefer: *"The reason why we go there is, the radio just talks, I don't ask it questions, it just talks and I don't see the person talking. But [at NAPHAM] we talk to them face to face. That's why we go there" (HIV+ Male partner, Couple #21).* Therefore, this project points to the significance of the experience of HIV and AIDS information which is as important as the information itself.

References

Abma, T. A., & Widdershoven, G. A. (2011). Evalution as a relationally responsible practice. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (4th ed., pp. 669-680). Thousand Oaks: Sage.

Aguilar, F. J. (1967). *Scanning the business environment*. New York: Macmillan.

Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research, 9*(3), 407-411. doi: 10.1177/104973239900900309

Airhihenbuwa, C. O., & Obregon, R. (2000). A critical assessment of theories/models used in health communication for HIV/AIDS. *Journal of Health Communication, 5* (Supplement 1), 5-15. doi: 10.1080/10810730050019528

Albright, K. (2007). *HIV/AIDS information seeking and healthcare communications in Sub-Saharan Africa*. Paper presented at the World Library and Information Congress: 73rd IFLA General Conference and Council, Durban, South Africa

Albright, K., & Kawooya, D. (2005a). The role of information in Uganda's reduction of HIV/AIDS prevalence: The Rakai Project and World Vision cases. *Proceedings of the American Society for Information Science and Technology, 41*(1), 3-10. doi: 10.1002/meet.1450410101

Albright, K., & Kawooya, D. (2005b). The Role of Information in Uganda's Reduction of HIV/AIDS: individual perceptions of HIV/AIDS information. *Information Development, 21*(2), 106-112. doi: 10.1177/0266666905054504

Albright, K., Kawooya, D., & Hoff, J. (2007). Information vaccine: Information and Uganda's reduction of HIV/AIDS. In A. Mcharazo & S. Koopman (Eds.), *Librarianship as a bridge to an information and knowledge society in Africa*. Munchen, Germany: K.G. Saur.

Allan, G. (1980). A Note on Interviewing Spouses Together. *Journal of Marriage and the Family, 42*(1), 205-210.

Allen, D. (2005). Phenomenology of religion. In J. R. Hinnells (Ed.), *The Routledge companion to the study of religion* (pp. 183-207). London: Routledge.

Allen, S., Meinzen-Derr, J., Kautzman, M., Zulu, I., Trask, S., Fideli, U., . . . Haworth, A. (2003). Sexual behavior of HIV discordant couples after HIV counseling and testing. *AIDS, 17*(5), 733-740. doi: 10.1097/01.aids.0000050867.71999.ed

Allwood, C. M. (2012). The distinction between qualitative and quantitative research methods is problematic. *Quality and Quantity, 46*(5), 1417-1429. doi: 10.1007/s11135-011-9455-8

Andrade, J., & May, J. (2004). *Cognitive psychology*. London; New York: BIOS Scientific Publishers.

Anglewicz, P. A., Bignami-Van Assche, S., Clark, S., & Mkandawire, J. (2010). HIV risk among currently married couples in rural Malawi: what do spouses know about each other? *AIDS and behavior, 14*(1), 103-112. doi: 10.1007/s11135-011-9455-8

Angrosino, M., & Rosenberg, J. (2011). Observations on observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research*. London: Sage Publications Ltd.

Arrehag, L., de Vylder, S., Durevall, D., & Sjöblom, M. (2006). *The impact of HIV/AIDS on the economy, livelihoods and poverty of Malawi*. Stockholm: Sida.

Ashbaugh, M. L. (2011). *Online pedagogical quality questioned: probing instructional designers' perceptions of leadership competencies critical to practice.* (PhD Thesis, Capella University, Minneapolis, Minnesota, USA). Retrieved from http://search.proquest.com

Audet, C. M., Sidat, M., Blevins, M., Moon, T. D., Vergara, A., & Vermund, S. H. (2012). HIV knowledge and health-seeking behavior in Zambézia Province, Mozambique. *SAHARA J : Journal of Social Aspects of HIV/AIDS Research Alliance, 9*(1), 41-46. doi: 10.1080/17290376.2012.665257

Auster, E., & Choo, C. W. (1993). Environmental scanning by CEOs in two Canadian industries. *Journal of the American Society for Information Science, 44*(4), 194-203.

Ayenew, A., Leykun, A., Colebunders, R., & Deribew, A. (2010). Predictors of HIV testing among patients with tuberculosis in North West Ethiopia: a case-control study. *PloS one, 5*(3). doi: 10.1371/journal.pone.0009702

Banda, F., & Mambwe, K. (2013). Fighting HIV/AIDS through popular Zambian music. *Muziki, 10* (Supplement 1), 1-12. doi: 10.1080/18125980.2013.852738

Bandawe, C. R. (2004). Revisiting human behaviour in relation to HIV/AIDS. *Malawi Medical Journal, 14*(2), 27-28.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215.

Bastien, S. (2008). Out-of-school and 'at risk'?: Socio-demographic characteristics, AIDS knowledge and risk perception among young people in Northern Tanzania. *International Journal of Educational Development, 28*(4), 393-404. doi: 10.1016/j.ijedudev.2007.11.005

Bastien, S. (2009). Reflecting and shaping the discourse: the role of music in AIDS communication in Tanzania. *Social Science & Medicine, 68*(7), 1357-1360. doi: 10.1016/j.socscimed.2009.01.030

Bastien, S. (2011). Fear appeals in HIV-prevention messages : young people's perceptions in northern Tanzania. *African Journal of AIDS Research, 10*(4), 435-449. doi: 10.2989/16085906.2011.646659

Bates, M. J. (2005). Information and knowledge: An evolutionary framework for information science. *Information Research, 10*(4). http://informationr.net/ir

Bekalu, M. A., & Eggermont, S. (2013). HIV/AIDS-related information needs of urban and rural residents of northwest Ethiopia: alerting the rural populace and meeting the progressive needs of the urban populace. *Information Development, 29*(2), 1-10. doi: 10.1177/0266666912468353

Belkin, N. (2005). Anomoulous state of knowledge. In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of information behavior* (pp. 44-48). Medford (N.J.): Information Today.

Benner, P. (1994). *Interpretive phenomenology : embodiment, caring, and ethics in health and illness*. Thousand Oaks, Calif: Sage Publications.

Beyeza-Kashesya, J., Ekstrom, A. M., Kaharuza, F., Mirembe, F., Neema, S., & Kulane, A. (2010). My partner wants a child: a cross-sectional study of the determinants of the desire for children among mutually disclosed sero-discordant couples receiving care in Uganda. *BMC Public Health, 10*(1), 247-258. doi: 10.1186/1471-2458-10-247

Bishop, M., & Foreit, K. (2010). Serodiscordant Couples in Sub-Saharan Africa: What Do Survey Data Tell Us? (H. P. I. Futures Group, Task Order 1, Trans.). Washington, DC: United States Agency for International Development

Blaikie, N. (2010). *Approaches to social enquiry: advancing knowledge*. Cambridge, UK: Polity.

Blaikie, N. (2011). *Designing social research : the logic of anticipation*. Cambridge, UK: Polity.

Bloom, B. S., Englehart, M. D., Furst, E. J., Hill, W. H., & Krathwohl, D. R. (1956). *Taxonomy of Educational Objectives: The Classification of Education Goals. Cognitive Domain. Handbook 1*. New York: Longman.

Blumberg, S. J. (2000). Guarding against threatening HIV prevention messages: An information-processing model. *Health Education & Behavior, 27*(6), 780-795. doi: 10.1177/109019810002700611

Bochner, A. P. (2000). Criteria Against Ourselves. *Qualitative inquiry, 6*(2), 266-272. doi: 10.1177/107780040000600209

Bollnow, O. F. (1961). Lived-space. *Philosophy Today, 5*(1), 31-39.

Borne, F. v. d. (2005). *Trying to survive in times of poverty and AIDS : women and multiple partner sex in Malawi*. Amsterdam, the Netherlands: Het Spinhuis.

Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research, 8*(1), 137-152. doi: 10.1177/1468794107085301

Boyd, E. M., & Fales, A. W. (1983). Reflective learning key to learning from experience. *Journal of Humanistic Psychology, 23*(2), 99-117. doi: 10.1177/0022167883232011

Brashers, D. E. (2006). A theory of communication and uncertainty management. In B. B. Whaley & W. Samter (Eds.), *Explaining Communication Contemporary Theories and Exemplars* (pp. 201-218). London: Routledge.

Bruce, C., Davis, K., Hughes, H., Partridge, H., & Stoodley, I. (2014). Information Experience: Contemporary Perspectives. In C. Bruce, K. Davis, H. Hughes, H. Partridge & I. Stoodley (Eds.), *Information Experience*. Bingley, UK: Emerald.

Bruce, H. (2005). Personal anticipated information need. *Information Research, 10*(3). http://InformationR.net/ir

Bryman, A. (2012). *Social research methods*. Oxford; New York: Oxford University Press.

Buckland, M. K. (1991). Information as Thing. *Journal of the American Society for Information Science, 42*(5), 351-360.

Bullington, J. (2013). *The expression of the psychosomatic body from a phenomenological perspective*. Dordrecht; New York: Springer.

Bunce, S., Partridge, H., & Davis, K. (2012). Exploring Information Experience Using Social Media during the 2011 Queensland Floods: A Pilot Study. *Australian Library Journal, 61*(1), 34-45. doi: 10.1080/00049670.2012.10722300

Bundorf, M. K., Baker, L., Singer, S., & Wagner, T. (2004). *Consumer demand for health information on the Internet*. Cambridge, Mass.: National Bureau of Economic Research.

Bunnell, R., Nassozi, J., Marum, E., Mubangizi, J., Malamba, S., Dillon, B., . . . Mermin, J. (2005). Living with discordance: knowledge, challenges, and prevention strategies of HIV-discordant couples in Uganda. *AIDS care, 17*(8), 999-1012. doi: 10.1080/09540120500100718

Burgoyne, A. D., & Drummond, P. D. (2009). Knowledge of HIV and AIDS in women in sub-Saharan Africa. *African journal of reproductive health, 12*(2), 14-31.

Burnett, G., Besant, M., & Chatman, E. A. (2001). Small worlds: Normative behavior in virtual communities and feminist bookselling. *Journal of the American Society for Information Science and Technology, 52*(7), 536-547. doi: 10.1002/asi.1102.abs

Burnett, G., & Jaeger, P. (2011). The Theory of Information Worlds and Information Behaviour. In A. Spink & J. Heinström (Eds.), *New Directions in Information Behaviour*. Bingley: Emerald.

Burnett, G., & Jaeger, P. T. (2008). Small Worlds, Lifeworlds, and Information: The Ramifications of the Information Behaviour of Social Groups in Public Policy and the Public Sphere. *Information Research, 13*(2). http://informationr.net/ir/13-2/paper346.html

Burnett, G., Jaeger, P. T., & Thompson, K. M. (2008). Normative behavior and information: The social aspects of information access. *Library & Information Science Research, 30*(1), 56-66. doi: 10.1016/j.lisr.2007.07.003

Buseh, A. G., Glass, L. K., McElmurry, B. J., Mkhabela, M., & Sukati, N. A. (2002). Primary and preferred sources for HIV/AIDS and sexual risk behavior information among adolescents in Swaziland, Southern Africa. *International Journal of Nursing Studies, 39*(5), 525-538. doi: 10.1016/S0020-7489(01)00058-X

Cain, D., Schensul, S., & Mlobeli, R. (2011). Language choice and sexual communication among Xhosa speakers in Cape Town, South Africa: implications for HIV prevention message development. *Health education research, 26*(3), 476-488. doi: 10.1093/her/cyq067

Campbell, C., Scott, K., Nhamo, M., Nyamukapa, C., Madanhire, C., Skovdal, M., . . . Gregson, S. (2013). Social capital and HIV competent communities: the role of community groups in managing HIV/AIDS in rural Zimbabwe. *AIDS care, 25* (Supplement 1), 114-122. doi: 10.1080/09540121.2012.748170

Campbell, C., Williams, B., & Gilgen, D. (2002). Is social capital a useful conceptual tool for exploring community level influences on HIV infection? An exploratory case study from South Africa. *AIDS care, 14*(1), 41-54. doi: 10.1080/09540120220097928

Carel, H. (2011). Phenomenology and its application in medicine. *Theoretical medicine and bioethics, 32*(1), 33-46. doi: 10.1007/s11017-010-9161-x

Carel, H. (2013). *Illness : the cry of the flesh*. Durham: Acumen Publishing.

Case, D. O. (2012). *Looking for Information : a survey of research on information seeking, needs and behavior*. Bingley (UK): Emerald Group Pub. Ltd.

Case, D. O., Andrews, J. E., Johnson, J. D., & Allard, S. L. (2005). Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *Journal of the Medical Library Association, 93*(3), 353-562.

Chatman, E. A. (1991). Life in a Small World: Applicability of Gratification Theory to Information-Seeking Behavior. *Journal of the American Society for Information Science, 42*(6), 438-449. doi: 10.1002/(SICI)1097-4571

Chatman, E. A. (1992). *The information world of retired women*. New York: Greenwood Press.

Chatman, E. A. (1996). The Impoverished Life-World of Outsiders. *Journal of the American Society for Information Science, 47*(3), 193-206. doi: 10.1002/(SICI)1097-4571(199603)47:3<193::AID-ASI3>3.0.CO;2-T

Chatman, E. A. (1999). A theory of life in the round. *Journal of the American Society for Information Science, 50*(3), 207-217. doi: 10.1002/(sici)1097-4571(1999)50:3<207::aid-asi3>3.0.co;2-8

Chen, H.-Y., & Boore, J. R. P. (2010). Translation and back-translation in qualitative nursing research: methodological review. *Journal of Clinical Nursing, 19*(1-2), 234-239. doi: 10.1111/j.1365-2702.2009.02896.x

Chimbiri, A. M. (2007). The condom is an 'intruder' in marriage: evidence from rural Malawi. *Social Science & Medicine, 64*(5), 1102-1115. doi: 10.1016/j.socscimed.2006.10.012

Chiu, T. M., & Eysenbach, G. (2011). Theorizing the health service usage behavior of family caregivers: a qualitative study of an internet-based intervention. *International Journal of Medical Informatics, 80*(11), 754-764. doi: 10.1016/j.ijmedinf.2011.08.010

Christians, C. G. (2011). Ethics and politics in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research*. Thousand Oaks: Sage.

Clouse, K., Schwartz, S. R., Van Rie, A., Bassett, J., Vermund, S. H., & Pettifor, A. E. (2015). High mobile phone ownership, but low Internet and email usage among pregnant, HIV-infected women attending antenatal care in Johannesburg. *Journal of telemedicine and telecare, 21*(2), 104-107. doi: 10.1177/1357633X14566569

Cohen, L., Manion, L., Morrison, K., & Bell, R. (2011). *Research methods in education*. London [etc.]: Routledge.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic phenomenological research : a practical guide for nurse researchers*. Thousand Oaks; London; New Delhi: Sage.

Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 48-71). New York: Oxford University Press.

Cole, C. (2012). *Information need : a theory connecting information search to knowledge formation*. Medford, New Jersey Information Today, Inc.

Coma, J. C. (2014). HIV prevention and marriage: Peer group effects on condom use acceptability in rural Kenya. *Social Science & Medicine, 116*(2014), 169-177. doi: 10.1016/j.socscimed.2014.07.005

Cooley, C. H. (1922). *Human nature and the social order*. Chicago: Alexander Street Press.

Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *BMJ: British Medical Journal, 335*(7609), 24 - 27. doi: 10.1136/bmj.39246.581169.80

Cox, J. (2014). *The Invention of God in Indigenous Societies*. Cambridge: Cambridge University Press.

Creswell, J. W. (2003). *Research design: qualitative, quantitative, and mixed method approaches*. Thousand Oaks, Calif.: Sage Publications.

Creswell, J. W. (2007). *Qualitative inquiry and research design : choosing among five traditions*. Thousand Oaks: Sage.

Creswell, J. W. (2011). Controversies in mixed methods research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research*. Thousand Oaks: Sage.

De Castro, A. (2003). Introduction to Giorgi's existential phenomenological research method. *Psicología desde el Caribe*(11), 45-56.

Dei, G. S. (2015). Integrating African proverbs in the education of young learners: the challenges of knowledge synthesis. In P. Sillitoe (Ed.), *Indigenous studies and angaged anthropology: the collaborative moment*. Burlington, VT: Ashgate.

Denscombe, M. (2003). *The good research guide for small-scale social research projects*. Maidenhead; Philadelphia: Open University Press.

Denzin, N. K., & Lincoln, Y. S. (2011a). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (pp. 1-19). Thousand Oaks: Sage.

Denzin, N. K., & Lincoln, Y. S. (2011b). *The Sage handbook of qualitative research*. Thousand Oaks: Sage.

Department for Health. (2010). Information standard. In U. K. Department for Health (Ed.). Basingstoke: The information Standard.

Dervin, B. (1983). *An overview of sense-making research concepts, methods, and results to date*. Paper presented at the International Communication Association Annual Meeting, Dallas. http://communication.sbs.ohio-state.edu/sense-making/art/artdervin83.html

Doyle, S. (2012). Reflexivity and the Capacity to Think. *Qualitative Health Research, 23*(2), 248–255. doi: 10.1177/1049732312467854

Edejer, T. T. (2000). Disseminating health information in developing countries: the role of the internet. *British Medical Journal, 321*(7264), 797-799. doi: 10.1136/bmj.321.7264.797

Edewor, N. (2010). Access to health information by people living with HIV/AIDS in Nigeria. *Library Philosophy and Practice, 2010*(FEB), 1-9. http://digitalcommons.unl.edu/libphilprac/321

Edriss, A., & Kaunda, C. (2000). Assessing Perceptions and Channels of HIV/AIDS Messages in sub-Saharan Africa: The Malawi Case. *UNISWA Research Journal of Agriculture, Science and Technology, 4*(2), 155-162.

Ehrich, L. C. (1999). Untangling the Threads and Coils of the Web of Phenomenology. *Education Research and Perspectives, 26*(2), 19-44.

Elbert, M., Fuegi, D., & Lipeikaite, U. (2011). Public libraries in Africa – agents for development and innovation? Current Perceptions of local stakeholders. *IFLA Journal, 38*(2), 148-165. doi: 10.1177/0340035212444512

Ellis, D. (2005). Ellis's model of information-seeking behavior. In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of information behavior*. Medford, N.J.: Information Today.

Ellis, D. (2011). The Emergence of Conceptual Modelling in Information Behaviour Research. In A. Spink & J. Heinström (Eds.), *New Directions in Information Behaviour* (Vol. 1). Bingley: Emerald Group Publishing Limited.

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2001). Participant observation and fieldnotes. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland & L. Lofland (Eds.), *Handbook of ethnography* (pp. 352-368). London: Sage.

Erdelez, S. (1999). Information Encountering: It's More Than Just Bumping into Information. *Bulletin of the American Society for Information Science and Technology, 25*(3), 26-29.

Erdelez, S. (2005). Information encountering In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of information behavior* (pp. 179-184). Medford (N.J.): Information Today.

Erlich, H. S. (2003). Experience - What is it? *The International Journal of Psychoanalysis, 84*(5), 1125-1147. doi: 10.1516/6HJ2-WKWW-6EYX-EYAA

Essien, E. J., Ross, M. W., Linares, A. C., & Osemene, N. I. (2000). Perception of reliability of human immunodeficiency virus/AIDS information sources. *Journal of the National Medical Association, 92*(6), 269-274.

Ezekiel, M. J., Leyna, G. H., Kakoko, D. C., & Mmbaga, E. J. (2012). Attitudes towards and perceptions of reproductive health needs of persons living with HIV/AIDS in rural Kilimanjaro, Tanzania. *Culture, health & sexuality, 14*(10), 1153-1165. doi: 10.1080/13691058.2012.717306

Ezekiel, M. J., Talle, A., Juma, J. M., & Klepp, K. (2009). "When in the body, it makes you look fat and HIV negative": The constitution of antiretroviral therapy in local discourse among youth in Kahe, Tanzania. *Social Science & Medicine, 68*(5), 957-964. doi: 10.1016/j.socscimed.2008.12.016

Fidel, R. (2012). *Human information interaction: an ecological approach to information behavior*. Cambridge, Mass.: MIT Press.

Fisher, K. E., Erdelez, S., & McKechnie, L. (2005). *Theories of information behavior*. Medford, N.J.: Information Today.

Ford, N., Miller, D., & Moss, N. (2003). Web Search Strategies and Approaches to Studying. *Journal of the American Society for Information Science and Technology, 54*(6), 473-489. doi: 10.1002/asi.10233

Ford, N., Miller, D., & Moss, N. (2005). Web search strategies and human individual differences: Cognitive and demographic factors, Internet attitudes, and approaches. *Journal of the American Society for Information Science and Technology, 56*(7), 741-756. doi: 10.1002/asi.20168

Foster, A., & Ford, N. (2003). Serendipity and information seeking: an empirical study. *Journal of Documentation, 59*(3), 321-340. doi: 10.1108/00220410310472518

Fox, C. J. (1983). *Information and misinformation : an investigation of the notions of information, misinformation, informing, and misinforming*. Westport, Conn.: Greenwood Press.

Fulton, C. (2005). Chatman's Life in the Round. In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of information behavior* (pp. 79-82). Medford, N.J: Information Today.

Gellaitry, G., Cooper, V., Davis, C., Fisher, M., Date, H. L., & Horne, R. (2005). Patients' perception of information about HAART: impact on treatment decisions. *AIDS care, 17*(3), 367-376.

Ghosh, J., & Kalipeni, E. (2005). Women in Chinsapo, Malawi: vulnerability and risk to HIV/AIDS. *SAHARA: Journal of Social Aspects of HIV/AIDS Research Alliance, 2*(3), 320-332. doi: 10.1080/17290376.2005.9724857

Gilovich, T., Keltner, D., & Nisbett, R. E. (2006). *Social psychology*. New York: W.W. Norton.

Giordano, J., O'Reilly, M., Taylor, H., & Dogra, N. (2007). Confidentiality and autonomy: The challenge (s) of offering research participants a choice of disclosing their identity. *Qualitative Health Research, 17*(2), 264-275. doi: 10.1177/1049732306297884

Giorgi, A. (1994). A phenomenological perspective on certain qualitative research methods. *Journal of Phenomenological Psychology, 25*(2), 190-220.

Giorgi, A. (1997). The Theory, Practice, and Evaluation of the Phenomenological Method as a Qualitative Research Procedure. *Journal of Phenomenological Psychology, 28*(2), 235-260.

Gitonga, M., Ballidawa, J., & Ndege, S. (2012). Challenges and Coping Strategies among Couples of Mixed HIV Status Presenting at a Large Comprehensive Care Centre in Eldoret, Kenya. *Journal of Biology, Agriculture and Healthcare, 2*(8), 18-27.

Glanz, K., Rimer, B. K., & Viswanath, K. (2008). *Health behavior and health education : theory, research, and practice*. San Francisco, CA: Jossey-Bass.

Glaser, B. G., & Strauss, A. L. (1999). *The discovery of grounded theory : strategies for qualitative research*. New York: Aldine de Gruyter.

Godbold, N. (2013). Listening to Bodies and Watching Machines: Developing Health Information Skills, Tools and Services for People Living with Chronic Kidney Disease. *Australian Academic & Research Libraries, 44*(1), 14-28. doi: 10.1080/00048623.2013.773859

Gombachika, B. C., Chirwa, E., Malata, A., & Maluwa, A. (2013). Sources of Information on HIV and Sexual and Reproductive Health for Couples Living with HIV in Rural Southern Malawi. *AIDS research and treatment, 2013*. doi: 10.1155/2013/235902

Gombachika, B. C., Fjeld, H., Chirwa, E., Sundby, J., Malata, A., & Maluwa, A. (2012). A Social Ecological Approach to Exploring Barriers to Accessing Sexual and Reproductive Health Services among Couples Living with HIV in Southern Malawi. *ISRN Public Health, 2012*(3), 1-13. doi: doi:10.5402/2012/825459

Gray, D. E. (2009). *Doing research in the real world*. Los Angeles: SAGE.

Green, E., & Witte, K. (2006). Can Fear Arousal in Public Health Campaigns Contribute to the Decline of HIV Prevalence? *Journal of Health Communication, 11*(3), 245-259. doi: 10.1080/10810730600613807

Green, G., & Sobo, E. J. (2000). *The endangered self: Managing the social risk of HIV*. London: Taylor & Francis Group.

Green, J., & Thorogood, N. (2004). *Qualitative methods for health research*. London; Thousand Oaks, Calif.: Sage Publications.

Greene, D. (2009). *An investigation of patient experiences of treatment in the cranial field of osteopathy.* (Master of Osteopathy, Unitec Institute of Technology, New Zealand). Retrieved from http://hdl.handle.net/10652/1344

Gregson, S., Mushati, P., Grusin, H., Nhamo, M., Schumacher, C., Skovdal, M., . . . Campbell, C. (2011). Social capital and women's reduced vulnerability to HIV infection in rural Zimbabwe. *Population and development review, 37*(2), 333-359. doi: 10.1111/j.1728-4457.2011.00413.x

Grinstead, O. A., Gregorich, S. E., Choi, K. H., & Coates, T. (2001). Positive and negative life events after counselling and testing: the Voluntary HIV-1 Counselling and Testing Efficacy Study. *AIDS 15*(8), 1045-1052. doi: DOI: 10.1097/00002030-200105250-00013

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks: Sage Publications.

Guest, G., Bunce, A., & Johnson, L. (2006). How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods, 18*(1), 59-82. doi: 10.1177/1525822X05279903

Guo, Y., & Goh, D. H. L. (2014). "I Have AIDS": Content analysis of postings in HIV/AIDS support group on a Chinese microblog. *Comput. Hum. Behav. Computers in Human Behavior, 34*, 219-226. doi: 10.1016/j.chb.2014.02.003

Hailemariam, T. G., Kassie, G. M., & Sisay, M. M. (2012). Sexual life and fertility desire in long-term HIV serodiscordant couples in Addis Ababa, Ethiopia: A grounded theory study. *BMC Public Health 12*(1), 1-12. doi: 10.1186/1471-2458-12-900

Hammersley, M., & Atkinson, P. (2007). *Ethnography Principles in Practice*. Hoboken: Taylor & Francis.

Hammond, M., Howarth, J., & Keat, R. (1991). *Understanding phenomenology*. Oxford: Blackwell.

Hayes, N. (2009). *Foundations of psychology*. Australia; London: South Western.

Heeren, G. A., Jemmott III, J. B., Tyler, J. C., Tshabe, S., & Ngwane, Z. (2011). Cattle for Wives and Extramarital Trysts for Husbands? Lobola, Men, and HIV/STD Risk Behavior in Southern Africa. *Journal of Human Behavior in the Social Environment, 21*(1), 73-81. doi: 10.1080/10911359.2011.534903

Hein, S. F., & Austin, W. J. (2001). Empirical and hermeneutic approaches to phenomenological research in psychology: A comparison. *Psychological methods, 6*(1), 3. doi: 10.1037/1082-989X.6.1.3

Heinström, J. (2014). The Emotional Valence of Information Experience: Relation to Personality and Approach to Studying. In C. Bruce, K. Davis, H. Hughes, H. Partridge & I. Stoodley (Eds.),

Information Experience: Approaches to Theory and Practice (Vol. 9, pp. 275 - 293). London: Emerald Group Publishing Limited.

Henn, M., Weinstein, M., & Foard, N. (2009). *A critical introduction to social research*. Los Angeles: SAGE.

Hepworth, M. (2007). Knowledge of information behaviour and its relevance to the design of people-centred information products and services. *Journal of Documentation, 63*(1), 33-56. doi: 10.1108/00220410710723876

Hepworth, M., Grunewald, P., & Walton, G. (2014). Research and practice: A critical reflection on approaches that underpin research into people's information behaviour. *Journal of Documentation, 70*(6), 1039-1053. doi: 10.1108/JD-02-2014-0040

Hersberger, J. (2003). Are the Economically Poor Information Poor? Does the Digital Divide affect the Homeless and Access to Information? *Canadian Journal of Information and Library Science, 27*(3), 45-64.

Hersberger, J. (2005). Chatman's Information Poverty. In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of Information Behaviour* (pp. 75-78). Medford (N.J.): Information Today.

Hodge, D. R., & Roby, J. L. (2010). Sub-Saharan African women living with HIV/AIDS: an exploration of general and spiritual coping strategies. *Social work, 55*(1), 27-37. doi: 10.1093/sw/55.1.27

Hogan, T. P., & Palmer, C. L. (2005). Information preferences and practices among people living with HIV/AIDS: results from a nationwide survey. *Journal of the Medical Library Association, 93*(4), 431-439.

Holloway, I., & Biley, F. C. (2011). Being a qualitative researcher. *Qualitative Health Research, 21*(7), 968-975. doi: 10.1177/1049732310395607

Houston, V., & Hovorka, A. (2007). HIV/AIDS messages in Malawi and their implications for effective responses. *African Journal of AIDS Research, 6*(3), 205-214. doi: 10.2989/16085900709490416

Howson, A. (2004). *The body in society : an introduction*. Cambridge, UK: Polity.

Huber, J. T., & Cruz, J. M. (2000). Information needs and information-seeking behaviors of HIV positive men and women. *Medical Reference Services Quarterly, 19*(3), 39-48. doi: 10.1300/J115v19n03_03

Huber, J. T., & Gillaspy, M. L. (1998). Social Constructs and Disease: Implications for a Controlled Vocabulary for HIV/AIDS. *Library Trends, 47*(2), 190-208.

Hughes, H. (2014). Researching information experience: methodological snapshots. In C. Bruce, K. Davis, H. Hughes, H. Partridge & I. Stoodley (Eds.), *Information experience: approaches to theory and practice* (Vol. 9, pp. 34-50). London: Emerald Group Publishing Limited.

Hyde, B. (2008). *Children and Spirituality Searching for Meaning and Connectedness*. London: Jessica Kingsley Publishers.

Jaeger, P., & Thompson, K. M. (2004). Social information behavior and the democratic process: Information poverty, normative behavior, and electronic government in the United States. *Library & Information Science Research, 26*(1), 94-107. doi: 10.1016/j.lisr.2003.11.006

Jaganath, D., Gill, H. K., Cohen, A. C., & Young, S. D. (2012). Harnessing Online Peer Education (HOPE): integrating C-POL and social media to train peer leaders in HIV prevention. *AIDS care, 24*(5), 593-600. doi: 10.1080/09540121.2011.630355

Johnson, J. D., & Case, D. O. (2012). *Health information seeking*. New York: Peter Lang.

Joint United Nations Programme on HIV/AIDS. (2009). *Partnership with Faith-based Organizations: UNAIDS Strategic Framework*. Geneva: UNAIDS.

Joint United Nations Programme on HIV/AIDS. (2010). *Getting to zero : 2011-2015 strategy*. Geneva, Switzerland: UNAIDS.

Joint United Nations Programme on HIV/AIDS. (2011). UNAIDS terminology guidelines. Geneva: Joint United Nations Programme on HIV/AIDS.

Joint United Nations Programme on HIV/AIDS. (2012a). Fast facts about HIV. Retrieved 8 February 2013, from http://www.unaids.org/en/resources/presscentre/fastfactsabouthiv/

Joint United Nations Programme on HIV/AIDS. (2012b). Global report UNAIDS report on the global AIDS epidemic : 2012. Geneva: UNAIDS.

Joint United Nations Programme on HIV/AIDS. (2013). *Global report UNAIDS report on the global AIDS epidemic : 2013*. Geneva: UNAIDS.

Joint United Nations Programme on HIV/AIDS. (2014). *The Gap Report*. Geneva: UNAIDS.

Jones, J. S. (2010). Origins and ancestors: a brief history of ethnography. In J. S. Jones & S. Watt (Eds.), *Ethnography in social science practice* (pp. 13-27). London: Routledge.

Julien, H., & Michels, D. (2004). Intra-individual information behaviour in daily life. *Information Processing & Management Information Processing & Management, 40*(3), 547-562. doi: 10.1016/S0306-4573(02)00093-6

Kalichman, S. C., & Simbayi, L. (2004). Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS care, 16*(5), 572-580. doi: 10.1080/09540120410001716360

Kalichman, S. C., Weinhardt, L., Benotsch, E., DiFonzo, K., Luke, W., & Austin, J. (2002). Internet access and Internet use for health information among people living with HIV-AIDS. *Patient education and counseling, 46*(2), 109-116. doi: 10.1016/S0738-3991(01)00134-3

Kalipeni, E., & Ghosh, J. (2007). Concern and practice among men about HIV/AIDS in low socioeconomic income areas of Lilongwe, Malawi. *Social Science & Medicine, 64*(5), 1116-1127. doi: 10.1016/j.socscimed.2006.10.013

Kamanga, M. (2014). *An optimality theoretic account and systemic functional linguistics analysis of the acquisition of cicewa idiom interpretation by cicewa speaking children in Malawi.* (PhD Thesis), University of the Western Cape.

Kamwendo, G. H. (2008). *'But having small houses spreads HIV': problems of language and Communication in health services in sub-Saharan Africa.* Paper presented at the International Conference on Globalisation and languages: Building on our rich heritage, Tokyo, Japan.

Kang'ethe, S., & Xabendlini, S. (2014). Exploring Myths Associated with HIV/AIDS with Examples from A Few Countries of the World. *Journal of Human Ecology, 46*(1), 55-61.

Kari, J. (2001). *Information seeking and interest in the paranormal: Towards a process model of information action.* (PhD), Tampere University Press.

Kaunda, S. G. (2013). Assessing Service Expectation and Perception of Public Library Users: Towards Development of User Needs and User Satisfaction Measurement Instruments for the National Library Service of Malawi. *Information and Knowledge Management, 3*(3), 30-40.

Kavinya, T. (2014). Opinions on government introduction of mandatory HIV testing. *Malawi Medical Journal, 22*(2), 62.

Kaye, D. (1995). Sources of information, formal and informal. *Management Decision, 33*(5), 13-15. doi: 10.1108/EUM0000000003898

Klenke, K. (2008). *Qualitative research in the study of leadership*. Bingley, UK: Emerald Group Pub.

Kneck, Å., Klang, B., & Fagerberg, I. (2011). Learning to live with illness: experiences of persons with recent diagnoses of diabetes mellitus. *Scandinavian journal of caring sciences, 25*(3), 558-566. doi: 10.1111/j.1471-6712.2010.00864.x

Koenane, M. L. J. (2014). The Phenomenology of Illness, Healing and Cure among Africans: Our Way or Theirs. *Mediterranean Journal of Social Sciences, 5*(6), 363-374. doi: 10.5901.mjss.2014.v5n6p363

Kuhlthau, C. C. (1993). A principle of uncertainty for information seeking. *Journal of Documentation, 49*(4), 339-355. doi: 0.1108/eb026918

Kutner, J. S., Steiner, J. F., Corbett, K. K., Jahnigen, D. W., & Barton, P. L. (1999). Information needs in terminal illness. *Social Science & Medicine, 48*(10), 1341-1352. doi: 10.1016/S0277-9536(98)00453-5

Kvale, S. (1983). The qualitative research interview: A phenomenological and a hermeneutical mode of understanding. *Journal of Phenomenological Psychology, 14*(2), 171-196. doi: 10.1163/156916283X00090

Kvale, S. (2006). Dominance through interviews and dialogues. *Qualitative inquiry, 12*(3), 480-500. doi: 10.1177/1077800406286235

Langdridge, D. (2007). *Phenomenological psychology : theory, research and method*. Harlow: Pearson Education.

Laverty, S. M. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods, 2*(3), 21-35.

LeCompte, M. D., & Schensul, J. J. (1999). *Designing & conducting ethnographic research*. Walnut Creek, Calif.: AltaMira Press.

LeMay, N. V., & Bocock, P. J. (2012). Building a national model for knowledge exchange in Malawi: findings from a health information needs assessment. *Journal of health communication, 17*(Supplement 2), 64-78. doi: 10.1080/10810730.2012.666623

Lewis, J., & Nicholls, C. M. (2014). Design issues. In J. Ritchie, J. Lewis, C. M. Nicholls & R. Ormston (Eds.), *Qualitative research practice : a guide for social science students and researchers*. Los Angeles: SAGE.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, Calif.: Sage Publications.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & L. Y. S. (Eds.), *The SAGE Handbook of Qualitative Research* (4th ed., pp. 97-128). Thousand Oaks: Sage.

Lingel, J., & Boyd, D. (2013). Keep it secret, keep it safe: Information poverty, information norms, and stigma. *Journal of the American Society for Information Science and Technology, 64*(5), 981-991. doi: 10.1002/asi.22800

Lloyd, A. (2009). Informing practice: information experiences of ambulance officers in training and on-road practice. *Journal of Documentation, 65*(3), 396-419. doi: 10.1108/00220410910952401

Lloyd, A. (2012). Information literacy as a socially enacted practice: Sensitising themes for an emerging perspective of people-in-practice. *Journal of Documentation, 68*(6), 772-783. doi: 10.1108/00220411211277037

Lloyd, A. (2014). Informed bodies: does the corporeal experience matter to information literacy practice. In C. Bruce, K. Davis, H. Hughes, H. Partridge & I. Stoodley (Eds.), *Information Experience: Approaches to Theory and Practice* (Vol. 9, pp. 85-99). London: Emerald Group Publishing Limited.

Lloyd, A., Bonner, A., & Dawson-Rose, C. (2013). The health information practices of people living with chronic health conditions: Implications for health literacy. *Journal of Librarianship and Information Science, 46*(3), 207 - 216. doi: 10.1177/0961000613486825

Longo, D. R. (2005). Understanding health information, communication, and information seeking of patients and consumers: a comprehensive and integrated model. *Health Expectations : an international journal of public participation in health care and health policy, 8*(3), 189-194. doi: 10.1111/j.1369-7625.2005.00339.x

Low-Beer, D., & Stoneburner, R. L. (2003). Behaviour and communication change in reducing HIV: is Uganda unique? *African Journal of AIDS Research, 2*(1), 9-21. doi: 10.2989/16085906.2003.9626555

Lubinga, E., & Jansen, C. (2011). 'No 'til we know.'Fela ba a tseba naa? Using African languages to communicate about HIV and AIDS to young South Africans. *Communicatio, 37*(3), 466-481.

Luckmann, B. (1970). The small life-worlds of modern man. *Social Research, 37*(4), 580-596.

Lwanda, J. C. (2011). "Edzi ndi dolo" (AIDS is mighty): singing HIV/AIDS 1980 - 2008. In G. Barz & J. M. Cohen (Eds.), *The culture of AIDS in Africa: hope and healing through music and the arts*. New York: Oxford University Press.

Magonya, L. (2012). *A pragmatic analysis of figurative language used in HIV/AIDS discourse in Kenia: a case study of english and Kiswahili messages.* (PhD Doctoral), University of Geneva.

Maguire, C., Kazlauskas, E. J., & Weir, A. D. (1994). *Information services for innovative organizations*. San Diego (California: Academic Press.

Malawi Government. (2003). *Information, Education and Communication implementation plan for working with 6 key social groups in Malawi*. Lilongwe, Malawi: Malawi National AIDS Commission.

Malawi Government. (2011). *Malawi Health Sector Strategic Plan 2011-2016: Moving towards equity and quality*. Lilongwe: Ministry of Health.

Malawi Government. (2012a). 2012 Global AIDS Response Progress Report: Malawi Country Report for 2010 and 2011. Lilongwe, Malawi: Malawi Government.

Malawi Government. (2012b). Integrated Household Survey 2010-2011: Household socio-economic characteristics report. Zomba, Malawi: National Statistical Office of Malawi.

Malawi Human Rights Commission. (2006). Cultural practices and their impact on the enjoyment of human rights, particularly the rights of women and children in Malawi. Lilongwe: Malawi Human Rights Commission.

Malawi National Aids Commission. (2007). *Malawi biological and behavioral surveillance survey 2006 and comparative analysis of 2004 BSS and 2006 BBSS*. Lilongwe, Malawi: National AIDS Commission.

Malawi National Aids Commission. (2012). *Malawi national HIV and AIDS monitoring and evaluation plan, 2011-2016*. Lilongwe: Office of the President and Cabinet, National AIDS Commission.

Manda, P. (2007). Socio-Cultural Determinants of HIV/AIDS Information Impact: Experiences from Babati District in Tanzania. In A. Mcharazo & S. Koopman (Eds.), *Librarianship as a bridge to an information and knowledge society in Africa* (pp. 167-182). München: K.G. Saur.

Marchionini, G. (2008). Human–information interaction research and development. *Library & Information Science Research, 30*(3), 165-174. doi: 10.1016/j.lisr.2008.07.001

Margolin, G., Chien, D., Duman, S. E., Fauchier, A., Gordis, E. B., Oliver, P. H., . . . Vickerman, K. A. (2005). Ethical issues in couple and family research. *Journal of Family Psychology 19*(1), 157-167. doi: 10.1037/0893-3200.19.1.157

Marks, D. F., Murray, B. E., Evans, B., & Estacio, E. V. (2011). *Health psychology : theory, research and practice*. London; Thousand Oaks, Calif.: SAGE.

Marshall, L. A., & Williams, D. (2006). Health information: does quality count for the consumer? How consumers evaluate the quality of health information materials across a variety of media. *Journal of Librarianship and Information Science, 38*(3), 141-156. doi: 10.1177/0961000606066575

Marton, F. (1988). Phenomenography: a research approach to investigating different understandings of reality. In R. R. Sherman & R. B. Webb (Eds.), *Qualitative research in education : focus and methods* (pp. 141-161). London: Falmer Press.

Mason, J. (2012). *Qualitative researching*. Los Angeles [etc.]: Sage.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research, 11*(3). http://www.qualitative-research.net/index.php/fqs/article/view/1428/3028

Mathiesen, K. (2004). What is information ethics? *Computers and Society, 34*(1), 6. doi: 10.1145/1050305.1050312

Mbananga, N., & Becker, P. (2002). Use of technology in reproductive health information designed for communities in South Africa. *Health Education Research, 17*(2), 195-209. doi: 10.1093/her/17.2.195

McCreary, L. L., Kaponda, C. P., Davis, K., Kalengamaliro, M., & Norr, K. F. (2013). Empowering Peer Group Leaders for HIV Prevention in Malawi. *Journal of Nursing Scholarship, 45*(3), 288-297. doi: 10.1111/jnu.12031

McCullagh, C. B. (1980). Historical Realism. *Philosophy and Phenomenological Research, 40*(3), 420-425.

Mchombu, K. J., Bruton, K., Cocks, A., & Evans, G. (2002). *Sharing knowledge for community development and transformation : a handbook*. [Ottawa]: Oxfam Canada.

McPherson, M., Smith-Lovin, L., & Cook, J. M. (2001). Birds of a feather: Homophily in social networks. *Annual review of sociology, 27*(1), 415-444.

Mertens, D. M. (2010). *Research and evaluation in education and psychology : integrating diversity with quantitative, qualitative, and mixed methods*. Los Angeles: Sage.

Merton, R. K. (1972). Insiders and Outsiders: A Chapter in the Sociology of Knowledge. *American Journal of Sociology, 78*(1), 9-47.

Meyers, Eric M., Fisher, Karen E., & Marcoux, E. (2009). Making Sense of an Information World: The EverydayLife Information Behavior of Preteens. *The Library Quarterly, 79*(3), 301-341. doi: 10.1086/599125

Mgbako, C., Higgins, T., & Fenrich, J. (2008). We Will Still Live: Confronting Stigma and Discrimination against Women Living with HIV/AIDS in Malawi. *Fordham International Law Journal, 31*(2), 289-342.

Minion, J., Todd. (2010). *The information world of gay men living with HIV.* ((PhD thesis, University of Sheffield, Sheffield, United Kingdom) Unpublished doctoral thesis), The University of Sheffield.

Mo, P. K. H., & Coulson, N. S. (2008). Exploring the communication of social support within virtual communities: A content analysis of messages posted to an online HIV/AIDS support group. *Cyberpsychology & behavior, 11*(3), 371-374. doi: 10.1089/cpb.2007.0118

Moran, D. (2000). *Introduction to phenomenology*. London; New York: Routledge.

Moran, D. (2012). *Husserl's crisis of the european sciences and transcendental phenomenology : an introduction*. Cambridge [England]: Cambridge University Press.

Morris, S. M. (2001). Joint and individual interviewing in the context of cancer. *Qualitative Health Research, 11*(4), 553-567. doi: 10.1177/104973201129119208

Morse, J. M. (2000). Determining Sample Size. *Qualitative health research., 10*(3), 3-5. doi: 10.1177/104973200129118183

Mosha, N. F., & Manda, P. (2012). HIV/AIDS information and changing sexual behaviour among undergraduate students in Tanzania. *ASLIB Proceedings: New Information Perspectives, 64*(5), 509-518. doi: 10.1108/00012531211263120

Moustakas, C. E. (1994). *Phenomenological research methods*. Thousand Oaks, Calif.: Sage.

Muchini, B., Benedikt, C., Gregson, S., Gomo, E., Mate, R., Mugurungi, O., . . . Halperin, D. (2011). Local Perceptions of the Forms, Timing and Causes of Behavior Change in Response to the AIDS Epidemic in Zimbabwe. *AIDS and behavior, 15*(2), 487-498. doi: 10.1007/s10461-010-9783-z

Mufune, P. (2005). Myths about condoms and HIV/AIDS in rural northern Namibia. *International Social Science Journal, 57*(186), 675-686. doi: 10.1111/j.1468-2451.2005.00584.x

Mukherjee, A., & Bawden, D. (2012). Health information seeking in the information society. *Health Information and Libraries Journal, 29*(3), 242-246. doi: 10.1111/j.1471-1842.2012.00997.x

Munthali, A., & Zulu, E. M. (2007). The timing and role of initiation rites in preparing young people for adolescence and responsible sexual and reproductive behaviour in Malawi. *African journal of reproductive health, 11*(3), 150-167. doi: 10.2307/25549737

Munthali, A., Zulu, E. M., Madise, N., Moore, A. M., Konyani, S., Kaphuka, J., & Maluwa-Banda, D. (2006a). *Adolescent sexual and reproductive health in Malawi: results from the 2004 National Survey of Adolescents*. New York: Alan Guttmacher Institute.

Munthali, A., Zulu, E. M., Madise, N., Moore, A. M., Konyani, S., Kaphuka, J., & Maluwa-Banda, D. (2006b). *Adolescent Sexual and Reproductive Health in Malawi: results from the 2004 National Survey of Adolescents, Occassional Report*. Guttmacher Institute. New York.

Mupenda, B., Duvall, S., Maman, S., Pettifor, A., Holub, C., Taylor, E., . . . Behets, F. (2014). Terms Used for People Living With HIV in the Democratic Republic of the Congo. *Qualitative Health Research, 24*(2), 209-216.

Musoke, M. G. N. (2007). Information behaviour of primary health care providers in rural Uganda: An interaction-value model. *Journal of Documentation, 63*(3), 299-322. doi: 10.1108/00220410710743261

Muthuswamy, V. (2005). Ethical issues in HIV/AIDS research. *Indian Journal of Medical Research, 121*(4), 601-610.

Mwale, M. (2014). Factors Determining Voluntary Counseling and Testing (VCT) for the Human Immunodeficiency Virus (HIV) among Low Income Women: Focus Group Findings from Rural, Urban, and Peri-Urban Women Groups in Lilongwe District-Malawi. *Journal of Basic and Applied Sciences, 10*, 306-316. doi: 10.6000/1927-5129.2014.10.40

Nahl, D. (2005). Affective load. In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of information behavior* (pp. 39-43). Medford (N.J.): Information Today.

Namuleme, R. K. (2013). *Information and HIV/AIDS: an ethnographic study of information behaviour* (PhD PhD Thesis), University of Sheffield.

Namyalo, S. (2010). *Challenges of translating and disseminating HIV/AIDS messages in a multilingual and multicultural nation: the case of Uganda*. Paper presented at the HIV/AIDS Communication Facing African Multilingualism: Exploratory Workshop. 16-20 November 2010, University of Lausanne.

Narayan, B., Case, D. O., & Edwards, S. L. (2011). The role of information avoidance in everyday-life information behaviors. *Proceedings of the American Society for Information Science and Technology, 48*(1), 1-9. doi: 10.1002/meet.2011.14504801085

National Research Council of Malawi. (2002). *Procedures and guidelines for the conduct of research in Malawi*. Lilongwe: National Research Council of Malawi.

National Statistical Office (NSO), & ICF Macro. (2011). *Malawi Demographic and Health Survey 2010*. Zomba, Malawi, and Calverton, Maryland, USA: NSO and ICF Macro.

Ngure, K., Mugo, N., Celum, C., Baeten, J. M., Morris, M., Olungah, O., . . . Shell-Duncan, B. (2012). A qualitative study of barriers to consistent condom use among HIV-1 serodiscordant couples in Kenya. *AIDS care, 24*(4), 509-516.

Niedźwiedzka, B. (2003). A proposed general model of information behaviour. *Information Research, 9*(1). http://informationr.net/ir/9-1/paper164.html

Nolen, S. (2008). *28 : stories of AIDS in Africa*. London: Portobello.

Nuffield Council on Bioethics. (2002). *The ethics of research related to healthcare in developing countries*. London: Nuffield Council on Bioethics.

Nwagwu, W. E. (2008). Effectiveness of sources of HIV/AIDS awareness in a rural community in Imo State, Nigeria. *Health Information and Libraries Journal, 25*(1), 38-45. doi: 10.1111/j.1471-1842.2007.00729.x.

O'Grady, L. (2008). Meeting health information needs of people with HIV/AIDS: sources and means of collaboration. *Health Information and Libraries Journal, 25*(4), 261-269. doi: 10.1111/j.1471-1842.2007.00764.x.

O'Reilly, M., & Parker, N. (2012). 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research, 13*(2), 190-197. doi: 10.1177/1468794112446106

Oheneba-Sakyi, Y., & Takyi, B. K. (2007). *African families at the turn of the 21st century*. Dubuque, Iowa: Kendall/Hunt Pub.

Organization, W. H. (2012). Guidance on couples HIV Testing and counselling including antiretroviral therapy for treatment and prevention in serodiscordant couples. *Geneva: World Health Organization*.

Oxford University Press. (2000). Oxford English dictionary. from http://dictionary.oed.com/entrance.dtl

Paas, S. (2013). *Chichewa/Chinyanja-English dictionary = English - Chichewa/Chinyanja mtanthauziramawu* (Fourth ed.). Blantyre [Malawi]: Christian Literature Action in Malawi.

Palmer, C. (2010). Observing with focus: field notes and data recording. In J. S. Jones & S. Watt (Eds.), *Ethnography in social science practice* (pp. 141-156). London: Routledge.

Pálsdóttir, Á. (2008). Information behaviour, health self-efficacy beliefs and health behaviour in Icelanders' everyday life. *Information Research, 13*(1). http://informationr.net/ir/13-1/paper334.html

Pálsdóttir, Á. (2010). The connection between purposive information seeking and information encountering: A study of Icelanders' health and lifestyle information seeking. *Journal of Documentation, 66*(2), 224-244.

Papadopoulou, E., Lee, G. K., & Fisher, K. E. (2013). *To love, honor, and inform from this site forward: A model of dyadic information behavior in online-initiated relationships*. Paper presented at the Annual Hawaii International Conference on System Sciences, Wailea, HI, USA

Partridge, H. L., & Yates, C. (2014). Researching Information Experience : Object and Domain. In C. S. Bruce, K. Davis, H. E. Hughes, H. L. Partridge & I. D. Stoodley (Eds.), *Information Experience : Approches to Theory and Practice*. Bingley, England: Emerald Group Publishing Limited.

Payne, G., & Payne, J. (2004). *Key concepts in social research*. London: SAGE.

Pendleton, V. E., & Chatman, E. A. (1998). Small world lives: implications for the public library. *Library Trends, 46*(4), 732-751.

Persson, A. (2011). HIV-negativity in serodiscordant relationships: The absence, enactment, and liminality of serostatus identity. *Medical anthropology, 30*(6), 569-590. doi: 10.1080/01459740.2011.561456

Persson, A. (2013). Notes on the concepts of 'serodiscordance'and 'risk'in couples with mixed HIV status. *Global public health, 8*(2), 209-220. doi: 10.1080/17441692.2012.729219

Peters, K., Jackson, D., & Rudge, T. (2008). Research on couples: are feminist approaches useful? *Journal of Advanced Nursing, 62*(3), 373-380. doi: 10.1111/j.1365-2648.2007.04558.x

Pettigrew, K. E., Fidel, R., & Bruce, H. (2001). Conceptual Frameworks in Information Behavior. *Annual Review of Information Science and Technology (ARIST), 35*(1), 43-78.

Pew Research Center. (2012). The Global Religious Landscape: A Report on the Size and Distribution of the World's Major Religious Groups as of 2010 /Pew Forum on Religion & Public Life. Washington, DC: Pew Research Center.

Pickard, A. J. (2007). *Research methods in information*. London: Facet.

Prata, N., Elizio, M., Mark, S., Morris, L., & Vahidnia, F. (2006). Relationship between HIV Risk Perception and Condom Use: Evidence from a Population-Based Survey in Mozambique. *International Family Planning Perspectives, 32*(4), 192-200.

Punch, K. F. (2006). *Introduction to social research : quantitative and qualitative approaches*. London: Sage publications.

Puri, J., Mechael, P., Cosmaciuc, R., Sloninsky, D., Modi, V., Berg, M., . . . Lyimo, S. (2010). *A study of connectivity in millennium villages in Africa*. Paper presented at the ACM International Conference Proceeding Series.

Putnam, R. D., Leonardi, R., & Nanetti, R. (1993). *Making democracy work : civic traditions in modern Italy*. Princeton, N.J.: Princeton University Press.

Ramlagan, S., Peltzer, K., Phaswana-Mafuya, N., & Aquilera, J. F. (2010). Support Group Needs for People Living with HIV and AIDS (PLWHA) in Communities around Durban, South Africa. *Journal of Psychology in Africa, 20*(1), 117-121. doi: 10.1080/14330237.2010.10820352

Randall, S., Coast, E., Compaore, N., & Wandera, S. O. (2011). The power of the interviewer: a qualitative perspective on African survey data collection. *Demographic Research, 28*(27). doi: 10.4054/DemRes.2013.28.27

Reddy, M., & Jansen, B. J. (2008). A model for understanding collaborative information behavior in context: A study of two healthcare teams. *Information Processing & Management, 44*(1), 256-273. doi: 10.1016/j.ipm.2006.12.010

Reddy, V. (2014). [Information experience in the context of information seeking methods by prospective students].

Regmi, K., Naidoo, J., & Pilkington, P. (2010). Understanding the Processes of Translation and Transliteration in Qualitative Research. *International Journal of Qualitative Methods, 9*(1), 16-26.

Robson, C. (2002). *Real world research : a resource for social scientists and practitioner-researchers*. Oxford [etc.]: Blackwell.

Rodrigues, R. J., Antony, J., Krishnamurthy, S., Shet, A., De Costa, A., & Cameron, D. W. (2013). What Do I Know? Should I Participate? Considerations on Participation in HIV Related Research among HIV Infected Adults in Bangalore, South India. *PloS one, 8*(2). doi: 10.1371/journal.pone.0053054

Rugalema, G. (2004). Understanding the African HIV pandemic: an appraisal of the contexts and lay explanation of the HIV/AIDS pandemic with examples from Tanzania and Kenya. In E. Kalipeni, S. Craddock, J. R. Oppong & J. Ghosh (Eds.), *HIV and AIDS in Africa: beyond epidemiology*. Malden, MA Blackwell Publishing.

Sairanen, A., & Savolainen, R. (2010). Avoiding health information in the context of uncertainty management. *Information Research, 15*(4). http://dialnet.unirioja.es/servlet/oaiart?codigo=3648233

Salazar, X., Figueroroa, C., Girón, J. M., & Cáceres, C. F. (2009). Gender, Masculinities and HIV/AIDS: Perspectives from Peru. In J. Boesten & N. Poku (Eds.), *Gender and HIV/AIDS: Critical Perspectives from the Developing World* (pp. 47-65). Farnham, England: Ashgate.

Sammarco, M. L., Ripabelli, G., Ferrucci, F., & Grasso, G. M. (2012). Source of information, knowledge, and sexual behaviour related to HIV/AIDS amongst university students in an inland territory of central Italy. *Italian Journal of Public Health, 4*(1), 53-58. doi: 10.2427/5903

Sandelowski, M., Knafl, G., & Voils, C. I. (2009). On quantitizing. *Journal of Mixed Methods Research, 3*(3), 208-222. doi: 10.1177/1558689809334210

Sanders, C. (2003). Application of Colaizzi's method: Interpretation of an auditable decision trail by a novice researcher. *Contemporary Nurse, 14*(3), 292-302. doi: 10.5172/conu.14.3.292

Saunders, M., Lewis, P., & Thornhill, A. (2009). *Research methods for business students*. New York: Prentice Hall.

Savolainen, R. (2008). *Everyday information practices : a social phenomenological perspective*. Lanham, Md.: Scarecrow Press.

Schutz, A. (1972). *The Phenomenology of the social world*. London: Heinemann Educational Books.

Schutz, A., & Luckmann, T. (1973). *The structures of the lifeworld*. Evanston, Ill.: Northwestern Univ. Pr.

Schwandt, T. A. (2000). Three epistemological stances for qualitative inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 189-213). Thousand Oaks, Calif: Sage Publications

Schwandt, T. A. (2001). *Dictionary of qualitative inquiry*. Thousand Oaks, Calif.: Sage Publications.

Schwandt, T. A. (2007). *The SAGE dictionary of qualitative inquiry*. Los Angeles, Calif.: Sage Publications.

Seale, C. (1999). *The quality of qualitative research*. London; Thousand Oaks, Calif.: Sage Publications.

Seale, C. (2002). Quality Issues in Qualitative Inquiry. *Qualitative Social Work, 1*(1), 97-110. doi: 10.1177/147332500200100107

Selman, L., Higginson, I. J., Harding, R., Agupio, G., Dinat, N., Mmoledi, K., . . . Panajatovic, B. (2009). Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: Multicentre qualitative study. *British Medical Journal, 338*(7703), 1127-1131. doi: 10.1136/bmj.b1326

Settle, R. B., & Alreck, P. (1989). Reducing buyers' sense of risk. *Journal of Marketing Communications*(January), 34-40.

Shosha, G. A. (2012). Employment of colaizzi's strategy in descriptive phenomenology: a reflection of a researcher. *European Scientific Journal, 8*(27), 31-43.

Sikwese, S., & Management Sciences for Health. (2009). Malawi: Assessment of information needs among health managers and health service providers. Knowledge for Health summary report. Lilongwe: Management Sciences for Health.

Silverman, D. (2011). *Qualitative research : issues of theory, method, and practice*. Los Angeles: Sage.

Skovdal, M., Campbell, C., Madanhire, C., Mupambireyi, Z., Nyamukapa, C., & Gregson, S. (2011). Masculinity as a barrier to men's use of HIV services in Zimbabwe. *Globalization and Health, 7*(1), 1-14. doi: 10.1186/1744-8603-7-13.

Sliep, Y., Poggenpoel, M., & Gmeiner, A. (2001). The experience of HIV reactive patients in rural Malawi--Part I. *Curationis, 24*(3), 56-65.

Sligo, F. X., & Jameson, A. M. (2000). The knowledge - behavior gap in use of health information. *Journal of the American Society for Information Science, 51*(9), 858-869. doi: 10.1002/(SICI)1097-4571(2000)51:9<858::AID-ASI80>3.0.CO;2-Q

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis : theory, method and research*. Los Angeles: SAGE.

Snöbohm, C., Friedrichsen, M., & Heiwe, S. (2010). Experiencing one's body after a diagnosis of cancer—a phenomenological study of young adults. *Psycho-Oncology, 19*(8), 863-869. doi: 10.1002/pon.1632

Squires, N. (2012). Is Malawi's AIDS programme sustainable? [Blog post]. Retrieved from https://dfid.blog.gov.uk/2012/10/23/is-malawis-aids-programme-sustainable/

Sutton, M., Anthony, M. N., Vila, C., McLellan-Lemal, E., & Weidle, P. J. (2010). HIV testing and HIV/AIDS treatment services in rural counties in 10 southern states: service provider perspectives. *The Journal of rural health, 26*(3), 240-247. doi: 10.1111/j.1748-0361.2010.00284.x

Svensson, L. (1997). Theoretical Foundations of Phenomenography. *Higher Education Research & Development, 16*(2), 159-171.

Taylor, B., & De Vocht, H. (2011). Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research, 21*(11), 1576-1587. doi: 10.1177/1049732311415288

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research : integrating quantitative and qualitative approaches in the social and behavioral sciences*. Los Angeles: SAGE.

The World Bank. (2013). Data. Retrieved 8 May, 2013, from http://data.worldbank.org/indicator/NY.GDP.MKTP.CD

The World Bank, & African Development Bank. (2012). *Transformational Use of Information and Communication Technologies in Africa*. Washington, DC: World Bank.

Tobias, B. Q. (2001). A descriptive study of the cultural mores and beliefs toward HIV/AIDS in Swaziland, Southern Africa. *International Journal for the Advancement of Counselling, 23*(2), 99-113.

Tucker, V. M. (2014). The Expert Searcher's Experience of Information. In C. Bruce, K. Davis, H. Hughes, H. Partridge & I. Stoodley (Eds.), *Information Experience : Approches to Theory and Practice* (Vol. 9, pp. 239 - 255). Bingley: Emerald Group Publishing Limited.

Turner, D. L., & Turrell, F. (2007). The Non-Existent God: Transcendence, Humanity, and Ethics in the Philosophy of Emmanuel Levinas. *Philosophia Philosophia : Philosophical Quarterly of Israel, 35*(3-4), 375-382.

Uganda National AIDS Commission. (2001). Twenty years of HIV/AIDS in the world: Evolution Of The Epidemic And Response In Uganda. Kampala: Uganda National AIDS Commission Secretariat.

United Nations. (2015). Sustainable Development Goals. Retrieved 6 July 2015, from http://www.un.org/sustainabledevelopment/sustainable-development-goals/

United Nations Children's Fund, World Health Organization, & Malawi Government. (2001). *Community IMCI baseline survey in Malawi*. Lilongwe: UNICEF : WHO : Malawi Gvt.

United Nations Development Programme (UNDP). (2014). *Human development report 2014: Sustaining human progress- reducing vulnerability and building resilience*. Lanham: Bernan Press.

University of Sheffield. (2012). *Academic diary and student handbook 2012-2013*. Sheffield: The University of Sheffield.

Uwah, C., & Wright, S. (2012). Socio-cultural identities, perceptions of sexuality/sexual behavior and cultural contexts as determinants of HIV and AIDS prevalence in Southern Africa. *World Journal of AIDS, 2*(1), 17-23. doi: 10.4236/wja.2012.21003.

Valle, R. S., & King, M. (1978). An introduction to existential-phenomenological thought in psychology. In R. S. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 3-16). New York: Oxford University Press.

Van Kaam, A. L. (1966). *Existential foundations of psychology*. Pittsburgh: Duquesne University Press.

Van Manen, M. (1984). Practicing Phenomenological Writing. *Phenomenology and Pedagogy, 2*(1), 36-69.

Van Manen, M. (1990). *Researching lived experience : human science for an action sensitive pedagogy*. [Albany, N.Y.]: State University of New York Press.

Van Manen, M. (1997). *Researching lived experience : human science for an action sensitive pedagogy*. London, Ont.: Althouse Press.

Van Manen, M. (2011). Hermeneutical phenomenology. Retrieved 9 April 2013, from http://www.phenomenologyonline.com/inquiry/orientations-in-phenomenology/hermeneutical-phenomenology/

van Nes, F., Abma, T., Jonsson, H., & Deeg, D. (2010). Language differences in qualitative research: is meaning lost in translation? *European Journal of Ageing, 7*(4), 313-316. doi: 10.1007/s10433-010-0168-y

van Teijlingen, E., & Hundley, V. (2002). The importance of pilot studies. *Nursing Standard, 16*(40), 33-36.

Vardy, P. (2005). Philosophy of religion. In J. R. Hinnells (Ed.), *The Routledge companion to the study of religion* (pp. 165-182). London: Routledge.

Veenstra, G., Luginaah, I., Wakefield, S., Birch, S., Eyles, J., & Elliott, S. (2005). Who you know, where you live: social capital, neighbourhood and health. *Social Science & Medicine, 60*(12), 2799-2818. doi: 10.1016/j.socscimed.2004.11.013

Veinot, T. C. (2009a). Interactive acquisition and sharing: Understanding the dynamics of HIV/AIDS information networks. *Journal of the American Society for Information Science and Technology, 60*(11), 2313-2332. doi: 10.1002/asi.21151

Veinot, T. C. (2009b). *A lot of people didn't have a chance to support us because we never told them Stigma management, information poverty and HIV/AIDS information/help networks*. Proceedings of the ASIST Annual Meeting 2009, Vancouver, Canada. http://hdl.handle.net/2027.42/78326

Veinot, T. C. (2010). 'We have a lot of information to share with each other': understanding the value of peer-based health information exchange. *Information Research, 15*(4), 15-24.

von Eckartsberg, R. (1998). Existential-Phenomenological Research. In R. S. Valle (Ed.), *Phenomenological inquiry in psychology : existential and transpersonal dimensions*. New York: Plenum Press.

Walker, J., Payne, S., Smith, P., & Jarrett, N. (2004). *Psychology for nurses and the caring professions*. Maidenhead: Open University Press.

Walter, M. (2010). *Social research methods*. South Melbourne, Vic.: Oxford University Press.

Weeks, A., Swerissen, H., & Belfrage, J. (2007). Issues, challenges, and solutions in translating study instruments. *Evaluation Review, 31*(2), 153-165. doi: 10.1177/0193841X06294184

White, K. (2002). *An introduction to the sociology of health and illness*. London; Thousand Oaks: Sage Publications.

Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in Qualitative Research. *Qualitative Health Research, 11*(4), 522-537. doi: 10.1177/104973201129119299

Wildemuth, B. M., & Case, D. O. (2010). Early information behavior research. *Bulletin of the American Society for Information Science and Technology, 36*(3), 35-38. doi: 10.1002/bult.2010.1720360309

Wiles, R. (2013). *What are qualitative research ethics?* London; New York: Bloomsbury Academic.

Williamson, V. H. (2005). *Hermeneutic phenomenological study of women's experinces of postnatal depression and health professional intervention* ((PhD thesis, University of Adelaide, Adelaide, Australia)), University of Adelaide. Retrieved from http://hdl.handle.net/2440/37724

Wilson, T. D. (1981). On user studies and information needs. *Journal of Documentation, 37*(1), 3-15. doi: 10.1108/eb026702

Wilson, T. D. (1997). Information behaviour: An interdisciplinary perspective. *Information Processing & Management, 33*(4), 551-572. doi: 10.1016/S0306-4573(97)00028-9

Wilson, T. D. (1999). Models in information behaviour research. *Journal of Documentation, 55*(3), 249-270. doi: 10.1108/EUM0000000007145

Wilson, T. D. (2000). Human information behavior. *Informing science, 3*(2), 49-56.

Wilson, T. D. (2003). Philosophical foundations and research relevance: issues for information research. *Journal of Information Science, 29*(6), 445-452. doi: 10.1177/0165551503296002

Wilson, T. D. (2005). Evolution in information behavior modeling Wilson's model. In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of information behavior.* (pp. 31-38). Medford N.J.: Information Today.

Wilson, T. D. (2010). Fifty years of information behavior research. *Bulletin of the American Society for Information Science and Technology, 36*(3), 27-34. doi: 10.1002/bult.2010.1720360308

Wilson, T. D., & Walsh, C. (1996). *Information behaviour : an inter-disciplinary perspective : a review of the literature*. London: British Library Research and Innovation Centre.

World Health Organisation. (2014a). Global Update on the Health Sector Response to HIV, 2014. Geneva: World Health Organisation.

World Health Organisation. (2014b). HIV/AIDS: Fact Sheet N°360. Retrieved 20 April, 2015, from http://www.who.int/mediacentre/factsheets/fs360/en/

World Health Organisation. (2015a). Gender inequalities and HIV. Retrieved 12 February 2015, from http://www.who.int/gender/hiv_aids/en

World Health Organisation. (2015b). Global Health Observatory (GHO) data. Retrieved 10 March 2015, from http://www.who.int/gho/hiv/epidemic_status/cases_all/en/

World Health Organisation, & Global Health Workforce Alliance. (2010). Global experience of community health workers for delivery of health related millennium development goals: a systematic review, country case studies, and recommendations for integration into national health systems. Geneva: World Health Organisation.

World Health Organisation, & Joint United Nations Programme on HIV/AIDS. (2009). *AIDS epidemic update 2009*. Geneva: Joint United nations programme on HIV/AIDS (UNAIDS).

World Health Organization. (2012). *Guidance on couples HIV testing and counselling including antiretroviral therapy for treatment and prevention in serodiscordant couples recommendations for a public health approach*. Geneva, Switzerland: World Health Organization.

World Health Organization, Joint United Nations Programme on HIV/AIDS, & UNICEF. (2011). *Global HIV/AIDS response epidemic update and health sector progress towards Universal Access : progress report 2011*. Geneva, Switzerland: World Health Organization.

Yakel, E. (2005). Archival intelligence. In K. E. Fisher, S. Erdelez & L. McKechnie (Eds.), *Theories of information behavior* (pp. 49-53). Medford (N.J.): Information Today.

Yates, C., Partridge, H., & Bruce, C. (2012). Exploring information experiences through phenomenography. *Library and Information Research, 36*(112), 96-119.

Yates, C., & Partridge, H. L. (2014). Exploring Information Literacy During a Natural Disaster : the 2011 Brisbane Flood. In C. Bruce, K. Davis, H. Hughes, H. Partridge & I. Stoodley (Eds.), *Information Experience : Approches to Theory and Practice*. London: Emerald Group Publishing Limited.

Yoder, P. S., Hornik, R., & Chirwa, B. C. (1996). Evaluating the program effects of a radio drama about AIDS in Zambia. *Studies in family planning, 27*(4), 188-203. doi: 10.2307/2137953

Young, S. D., Shoptaw, S., Harrell, L., Jaganath, D., & Cohen, A. C. (2013). Feasibility of recruiting peer educators for an online social networking-based health intervention. *Health Education Journal, 72*(3), 276-282.

Zahavi, D. (2005). *Subjectivity and selfhood : investigating the first-person perspective*. Cambridge, Mass.: MIT Press.

Zhou, Y. R. (2010). The phenomenology of time: Lived experiences of people with HIV/AIDS in China. *Health:, 14*(3), 310-325. doi: 10.1177/1363459309358596

Zukoski, A. P., Thorburn, S., & Stroud, J. (2011). Seeking information about HIV/AIDS: a qualitative study of health literacy among people living with HIV/AIDS in a low prevalence context. *AIDS care, 23*(11), 1505-1508. doi: 10.1080/09540121.2011.582077

Appendix I: Ethics approval certificate University of Sheffield

Information School Research Ethics Panel

Letter of Approval

Date: 23rd July 2013

 TO: Kondwani Wella

The Information School Research Ethics Panel has examined the following application:

Title: Experiencing HIV and AIDS information: a phenomenological study of serodiscordant couples in Malawi

Submitted by: Kondwani Wella

And found the proposed research involving human participants to be in accordance with the University of Sheffield's policies and procedures, which include the University's '*Financial Regulations*', '*Good Research Practice Standards'* and the '*Ethics Policy Governing Research Involving Human Participants, Personal Data and Human Tissue'* (Ethics Policy).

This letter is the official record of ethics approval by the School, and should accompany any formal requests for evidence of research ethics approval.

Effective Date: 1st August 2013

Dr Angela Lin

Research Ethics Coordinator

Appendix II: Ethics approval certificate University of Malawi

CERTIFICATE OF ETHICS
APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.08/13/1439 – Experiencing HIV and AIDS Information : a phenomenological study of serodiscordant couples in Malawi by Mr. K. Wella

On 13 September 2013

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Dr. F. Dzinjalamala- Vice-Chairman (COMREC)

Approved by
College of Medicine

1 8 SEP 2013

(COMREC)
Research and Ethics Committee

18th Sept 2013
Date

Appendix III: Pilot interview guide

Arrival A chat about general issues such as the weather, farming etc.	
Introducing the research topic	
• Introduce myself • How long the interview will last • Introduce the subject of the research and explain that I will read the information sheet for more details. • Read the information sheet • Ensure that the environment is secure for confidentiality of the couples • Request the partners to sign the consent form • Ask for their permission to record the interview	
The Interview Do you need HIV and AIDS information? Can you describe to me the (specific) types of information you need as a couple? As individuals?	
Is all HIV and AIDS information you need available?	
What sources do you get HIV and AIDS information from? • Insider sources vs outsider sources	
How do you experience HIV and AIDS information? (Explore feelings or emotions when encountering or seeking HIV and AIDS information. What is it like to encounter or seek HIV and AIDS information?) Probes • HIV and AIDS information, and culture • HIV and AIDS information, and religion • HIV and AIDS information, and family ties • False HIV and AIDS information	
Can you tell specific examples of sources of HIV and AIDS information you find valuable? (Why is it important?) Are there some HIV and AIDS information you don't like getting? Are there some HIV and AIDS information you don't use after getting them? Is there HIV and AIDS information you keep receiving but you feel is not valuable? Is there HIV and AIDS information you hear or get that you know is false?	
Were you looking for information before you tested positive? Do you share information? (as partners or with others)	
Concluding the interview Do you have any questions?	

Appendix IV: Revised interview guide – post pilot

- Introduce myself - How long the interview will last - Introduce the subject of the research and explain that I will read the information sheet for more details. - Read the information sheet - Ensure that the environment is secure for confidentiality of the couples - Request the partners to sign the consent form - Ask for their permission to record the interview	
The Interview Tell me briefly how your life has been since the HIV testing? Can you describe to me the (specific) types of information you need as a couple? As individuals?	
Is all HIV and AIDS information you need available?	
What sources do you get HIV and AIDS information from? Insider sources vs outsider sources	
How do you experience HIV and AIDS information? (Explore feelings or emotions when encountering or seeking HIV and AIDS information. What is it like to encounter or seek HIV and AIDS information?) Probes - HIV and AIDS information, and culture - HIV and AIDS information, and religion - HIV and AIDS information, and family ties - False HIV and AIDS information	
Can you tell specific examples of sources of HIV and AIDS information you find valuable? (Why is it important?) Are there some HIV and AIDS information you don't use after getting them? Is there HIV and AIDS information you hear or get that you know is false?	
Were you looking for information before you tested positive? Do you share information? (as partners or with others)	
Concluding the interview Do you have any questions?	

Appendix V: NVivo analysis screen shots

Appendix VI: Codes exported from NVivo

	Name	Description
1	Accessibility	Information is in inaccessible formats or language
2	Anxiety	HIV and AIDS information making couples anxious or triggers anxiety
3	As a warning	Couples experience HIV and AIDS information as a warning of the dangers of sexual behaviours
4	As carers	Couples or partners experience information as carers of their spouses or their children
5	Availability	Availability or non-availability of HIV and AIDS information for serodiscordant couples
6	Inadequate	Though available, HIV and AIDS is found to be inadequate or superficial
7	Barriers to HIV and AIDS information	Factors or things or practices that prevent couples from accessing HIV and AIDS information they know is available
8	Insiders and outsiders	Some HIV and AIDS information sources reject HIV negative partners
9	Comparing and choosing sources	Couples compare information sources in terms of trustworthiness
10	Conflicting information	Information conflict between sources
11	Some information is divisive	some information, especially from informal sources is aimed at breaking up couples
12	Couples or partner as source of information	Some couples or individual partners had desire to be or were sources of HIV and AIDS information
13	Culture	HIV and AIDS information is measured against culture; and messages that perpetuated by culture; couples made sense of HIV and AIDS information based on culture
14	Deception	Couples feel some information given to them has hidden agendas
15	Fraudulent and exploitation	HIV and AIDS sources/providers are fraudulent and exploitative. Couples feel exploited.
16	Denial	Avoidance of information that is perceived as threatening/ failure to acknowledge the reality of the situation
17	Distressing	Couples found some HIV and AIDS information distressing e.g. when it portrays them as being promiscuous
18	Disappointment	disappointed with information sources that give out wrong HIV and AIDS information; and informal sources that demonise people living with HIV

19	Fear, threatening	Some HIV and AIDS information (meant for people that are negative) use threats to influence behaviour change
20	Encouragement (liberating)	Most formal sources allay fears that are instilled in couples by informal sources
21	Gender	Gender differences in the way people act on information; inadequate HIV and AIDS information addressing gender based violence that come because of sero-status
22	Guilt	Couples receive information with guilt; and HIV negative partners instil a sense of guilt in their spouses using HIV and AIDS information
23	Happiness, lifeline	Couples welcome HIV and AIDS information as the only hope to keep them alive
24	HIV and AIDS information is for them	Before testing positive couples said they viewed HIV and AIDS information was for sex workers; HIV negative partners viewed HIV and AIDS information to be for their HIV positive spouse only.
25	Human rights and gender based violence	inadequate HIV and AIDS information addressing gender based violence that come because of sero-status
26	Information medium (Mode of delivery)	the form in which information is transmitted; couples also had preferences for some modes of delivery of information
27	Information needs	
28	Encouragement	Couples needed encouraging information, especially for couples with imminent separation
29	Information about AIDS	Couples still need information about HIV; and information about AIDS
30	Information about business loans	Because of low economic status couples needed information about business loans to earn extra money
31	Information about medication	ARVs keep changing, couples needed information about new ARV regimens and side effects
32	Information about serodiscordance	Couples needed clear information that explains serodiscordance
33	Nutrition	Need for information about locally available foods for HIV positive people; also need for guide book on nutrition
34	Personal health information	Couples want to constantly know about their health
35	Reproductive health and sexuality	Couples needed information on child bearing, how to protect the unborn baby and the HIV negative partner
36	Skills training	Information about support group leadership skills training; HIV and AIDS advocacy skills training
37	Social support	Couples need information about social support; child support

38	Information seeking	
39	information searching after testing positive	Were couples looking/searching for information after being found HIV positive
40	information searching before testing positive	Were couples looking/searching for information before being found HIV positive
41	Information sources	Places or people where couples get HIV and AIDS information
42	Credibility	Comments about credibility of HIV and AIDS information
43	Information sources characteristics	information sources characteristics that attracted couples to seek information
44	Motive	Couples were interested to know the motive of information providers/sources before accepting information
45	Insolubility of marriage	Religious or cultural based information that teaches that marriage is insoluble
46	Reminder of separation	HIV and AIDS information reminds partners of (imminent) separation from their spouses
47	Insulted by HIV and AIDS information	Some HIV and AIDS information is insulting to couples
48	Lies	Couples do not believe some HIV and AIDS information
	Moral judgement of behaviour	Statements that indicated a feeling that HIV and AIDS information is a judgement of their behaviour
49	Loss of social networks	HIV and AIDS information is a constant reminder of loss of children, spouses and other relatives to AIDS
50	Mythical	A compilation of HIV and AIDS information held by couples that was mythical
51	Non-verbal	Some actions that communicate HIV and AIDS information
52	Not appealing	HIV and AIDS information is not appealing and fails to attract people
53	Not clear	
54	Confusing	the same phenomenon is explained in many different ways
55	Evolving	HIV and AIDS information keeps changing in content and clarity
56	Not regulated	Information is not checked for consistency and correctness (especially informal sources)
57	Pain and bitterness	Experiencing HIV and AIDS information with pain; couples feel blamed
58	Places	Places where couples experienced HIV and AIDS information
59	Poverty	HIV and AIDS information reminds of loss of breadwinners and

		resulting poverty
60	Relationships	Informational relationships couples have; couples experience HIV and AIDS information within their relationships with others
61	With community	
62	With family	
63	With spouse	
64	With the church	
65	Religion	Religion is used to make sense of HIV and AIDS information; religious HIV and AIDS messages
66	Condom use	religious information about condom use
67	Contradicts the religious form of marriage	HIV and AIDS information promotes practices that are against the religious form of marriage
68	Healing	Religious messages that claim healing of HIV; attitudes towards religious healing of HIV
69	Reminder of loss of children or relatives	(to be merged with loss of social networks)
70	Stages	HIV and AIDS information is experienced in stages from pre-diagnosis to now (time of interview)
71	Stigma and discrimination	Feeling being discriminated by HIV and AIDS information
72	Survival guide	HIV and AIDS information as a "How to" guide
73	Health education	HIV and AIDS information as a guide for health living
74	Information about HIV and AIDS	As a source of knowledge about HIV and AIDS
75	Information about loans	As a source of information about loans to start businesses
76	Medication	As a source of information about ARVs
77	Nutrition	nutrition guide
78	Parenting tool	Guide for caring and protecting children from HIV; how to support children after death
79	Reproductive health and sexuality	Guide on how to protect each other; protect un-born baby
80	Social support information	Source of information about social support for people living with AIDS
81	Suspicion and mistrust	Partners not trusting each other, especially when information puts negative labels on people living with HIV
82	Blamed	Couples feel they are blamed by the messages

83	Taboo, too explicit	Based on culture or religion HIV and AIDS information is considered too explicit
84	Trapped and feeling defeated, vulnerability	Couples feel they are trapped in a serodiscordant marriage
85	Uncertainty	HIV and AIDS information does not give hope for the future
86	Useless, doubtful	Some information is thought to be useless or couples doubt its authenticity

Appendix VII: Free imaginative variation

Theme	Free Imaginative Variation result
Information sources	Essential theme
Availability and accessibility	Essential theme
Content	Non-essential theme – content was talked about in relation to quality and authenticity, therefore this theme is subsumed by Information standards
Information standards	Essential theme
Small world experience of HIV and AIDS information	Essential theme – is the overarching framework of interpretation of the results. The theme is modified to Life-world with sub-themes lived body, lived others, lived space and lived time
Decision making guide	Essential theme
Social networks (others)	Essential theme
Culture	Essential theme
Poverty	There is a trend in the interviews where it appeared couples to thought I was coming from some organisation that would bring financial support for people living with HIV. As such at the beginning of the interviews they emphasised their poverty.
Gender	Essential theme
Negative emotions	Essential theme but it was merged with Positive emotions into one theme Emotional
Positive emotions	Essential theme but it was merged with Negative emotions into one theme Emotional
Denial	Essential theme
Uncertainty and despondency	Essential theme
Morality of the information provider	Subsumed by Moral and religious values
Moral and religious values	Essential theme
Moral reading/judgements of behaviour	Subsumed by Moral and religious values

Appendix VIII: Thematic transformations

Availability and accessibility

HIV and AIDS information for serodiscordant couples is either available or not available. Some institutions that are traditionally expected to be sources of HIV and AIDS information are found to be silent. On the other hand, information was found to be available but not accessible because of format or language.

Health care decision making guide

Serodiscordant couples were face with difficult and challenging health situations. HIV and AIDS information was experience as a tool to aid decision making. In some cases it was viewed as a guide for making those decisions.

Information standards

HIV and AIDS information is experienced as a commodity which has to conform to some standards. Serodiscordant couples experienced HIV and AIDS information as a commodity lacking standards.

Small world experience of HIV and AIDS information

Social networks (others)

Serodiscordant couples occupy their world with other people. These are either HIV positive or HIV negative. As such, the couples experience HIV and AIDS information with other people. Some of the meanings they draw from HIV and AIDS information are co-constructed. The others are ordinary people living in the community, community leaders, professionals working in institutions that deal with HIV and AIDS or religious leaders.

Culture

Culture is the major contextual framework within which HIV and AIDS information is experienced.

Gender

The two partners' interactions had gender undertones. Male partners disregarded HIV and AIDS information just to show their superiority.

Negative emotions

HIV and AIDS information triggered negative emotions of fear, anxiety, distress, disappointment, pain and bitterness. HIV and AIDS information is as complicated as the pandemic itself. Information that targets people that are HIV negative talks about the dangers of HIV and this is threatening to serodiscordant couples. The HIV negative partner, bound by marriage vows, feels trapped and HIV and AIDS information triggers anxiety, fear and emotional pain.

Positive emotions

For couples that had lived with HIV for a long time they had accepted the illness and started living positively. Although these couples experienced HIV and AIDS information with negative emotions, overall they were positive about their lives. They used HIV and AIDS information to reach out to other people. They also used personal health information such as their HIV status to convince other people in their community to go for testing.

Denial

Serodiscordant couples experience HIV and AIDS information with denial. HIV and AIDS information is threatening and trigger negative emotions. As a coping strategy couples did not acknowledge the anxiety that comes from HIV and AIDS information.

Uncertainty and despondency

The complexity of HIV and AIDS brings uncertainty and despondency. The uncertainty and despondency is compounded by serodiscordance as the two partners are united by marriage vows, traditional and religious expectations on marriages. HIV and AIDS related issues that cause the uncertainty and despondency are communicated to serodiscordant couples in HIV and AIDS information. As a result, HIV and AIDS information is a source of uncertainty and despondency for serodiscordant couples.

Moral and religious values

Moral and religious values are part of the contextual framework within which HIV and AIDS information is experienced. In the absence of treatment or vaccine serodiscordant couples find hope in religion. As such HIV and AIDS information is experienced with the context of moral and religious values.

Appendix IX: Sample field notes

22nd August 2013

I met two volunteers who support people infected and affected with HIV in Senti, Lilongwe District. When I explained details about my study they were not supportive. They expressed displeasure with people who come to their area to collect names of people living with HIV and orphans but never come back to support the people. They claimed that these people work on enriching themselves with resources meant for people living with HIV.

After explaining that I was a student they softened and promised to assist me.

23rd August 2013

I visited Paradiso HIV Support Group in Area 24, Lilongwe. The manager was supportive and he told me that she could recall four names of couples on their register that were serodiscordant. We agreed that I go back after I obtain COMREC approval. She promised to check the register again for more serodiscordant couples.

28th August 2014

I visited Kanengo AIDS Support Organisation (KASO). The manager was out visiting families in the villages. I went back later in the day and met the manager.

The manager told me that KASO had serodiscordant couples on their register and mostly women in these couples were HIV positive. Women tested HIV positive at the antenatal clinic, when the husbands tested negative the couples separated. There was no serodiscordant couple left. At this point I started thinking about the possibility of interviewing partners that had separated.

The manager advised me to check at Kaggwa Catholic Parish. I visited Kaggwa Parish Home Based Care. I met a volunteer who was himself in a serodiscordant relationship and he accepted to be interviewed. He also promised to identify other couples.

I went back to Senti. When I met the two volunteers they wanted to know if I was planning to implement projects so that they could stop working with their collaborators and work with me. I explained that I was only a student.

I met one couple the volunteers had identified, the couple agreed to be interviewed.

The volunteers warned me that many couples may not be willing to participate for fear of being exploited.

30th August 2013

I visited Face to Face. I was told that they only work with youths. However, the Executive Director promised to link me up with Community Based Organisations (CBO) that are in their catchment area. He also told me that they have teen clubs and he would find out if some of children's parents are serodiscordant.

I went back to Kaggwa Parish where I met the manager. She was supportive and identified one more serodiscordant couple. We agreed I would go back the next Wednesday to meet the couple.

4th September 2013

I went to Kaggwa Parish. I met one couple that was identified. The couple accepted to participate in the study and be interviewed in their home. When I was leaving the husband followed me and confided in me that he married the woman after her first husband passed away. He revealed that he knew the woman was HIV positive.

3rd September 2013

I had a telephone conversation with the Village Chief of Senti. He told me that he had identified another volunteer who would assist in identifying more couples.

9th September 2013

I met the Executive Director of Coalition of Women Living with AIDS (COWLHA). She agreed to assist in recruiting serodiscordant couples after COMREC approval. She told me that they have two serodiscordant couples in Dedza and Blantyre. The husband in another couple passed away. She also said they have another couple where both partners are highly educated and would articulate the issues I was investigating but they were not willing to disclose their HIV status to the public.

10th September 2013

I had an informal chat with a potential participant from Kaggwa Parish. He asked if the recorded interviews would be broadcast on the radio. I explained what the interviews would be used for and the confidentiality procedures that were in place.

17th September 2013

I interviewed a couple where the husband was HIV negative. The husband was so disruptive, and corrected every statement I made. However, when I got rapport with the couple the husband

turned out to be a good interviewee. He thought I was a medical doctor apparently because semantically the local language translation of PhD student is the same as for medical doctor. So he asked me to explain what he can do to remain negative while in a serodiscordant relationship.

When the husband briefly went out, the wife confided in me that the man was not his first husband. Her first husband died of AIDS. Similarities with the man from Kaggwa Parish.

24th September 2013

In interviewed a man who had separated from his wife. He told me that his father married and a daughter from that marriage died of AIDS. That death is what gave him confirmation that HIV is real. He also told me when he tested HIV positive he had tested negative 10 times prior.

Appendix X: Sample photographs collected from serodiscordant couples' homes
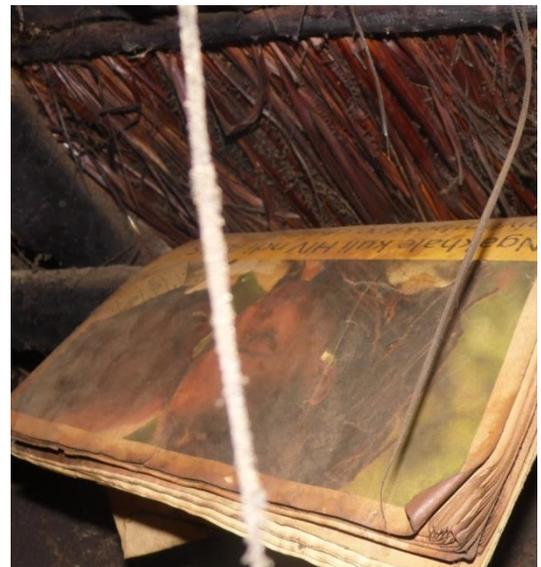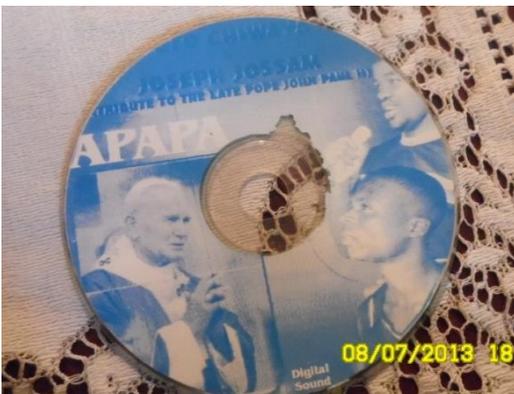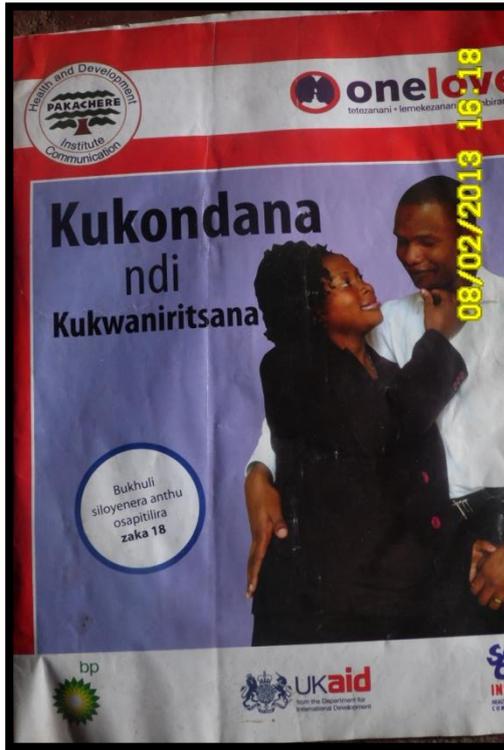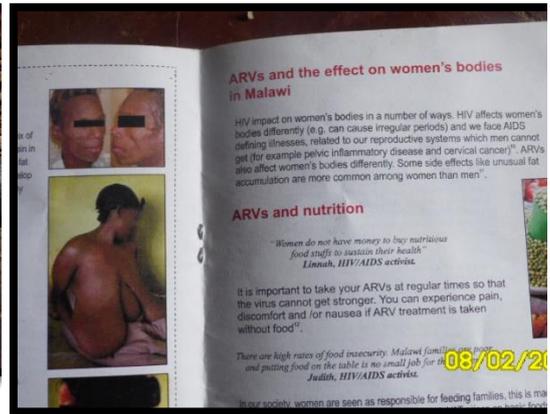
Appendix XI: Thematic analysis 1

Moral and Religious values

Guilt (Sin)
Fraudulent and exploitation
Too explicit and taboo
Guilt (sin)
Deception
Condom use in marriage
Blamed
Contradicts religious and traditional concept of marriage
HIV and AIDS information as a moral yardstick
Insulted by information
Credibility

Availability

Conflicting information
Silence
Accessibility
Availability
Not regulated
Information medium (Mode of delivery)

Positive emotions

Pain and bitterness
Fear, threatening
Anxiety
Distressing
Denial

Appendix XII: Thematic analysis 2

1st Order Category (Codes)	2nd Order Category (Themes)	3rd Order Category
Silence	Availability and accessibility	**Technical**
Inadequate information		
Translation		
Language (not regulated, translation)		
Couples as sources of information		
Mode of delivery		
Scarce		
Cost		
illiteracy		
Not clear/confusing	Content	
Evolving		
Not regulated		
Health education	Health care decision making guide	
Information about HIV and AIDS		
Information about business loans		
Medication		
Nutrition		
Parenting tool		
Reproductive and sexual health		
Social support		
Not regulated	Information standards	
Not clear/confusing		
Insiders and outsiders	Small world experience of HIV and AIDS information	**Sociological aspects**
Information sources characteristics • Interactivity • Credibility • Motive		
HIV and AIDS information is for them		
Spying		
Comparing and choosing sources		
Untrustworthy sources		
Spouse (Partners' co-experience and lone experience)	Social networks (others)	
Family		
Community		

Health workers		
Church		
Couples or partner as source of information		
Taboo and explicit	Culture	
Marriage		
Beliefs		
Children		
Contradicts religious and traditional concept of marriage		
	Poverty	
Male dominance	Gender	
Gender based violence		
Pain and bitterness	Negative emotions	**Psychological aspects**
Disappointment		
Fear, threatening		
Distressing		
Anxiety		
Happiness, lifeline	Positive emotions	
Encouraging, liberating		
Accepting illness		
Happiness/lifeline	Denial	
Distressing		
Anxiety	Uncertainty and despondency	
Fear of separation		
Silence		
Inadequate information		
Fraudulent and exploitation	Morality of the information provider	**Moral and religious values**
Deception		
Credibility		
Too explicit and taboo	Moral and religious values	
Condom use in marriage		
Guilt (Sin)		
Contradicts religious and traditional concept of marriage		
Guilt (sin)	Moral reading/judgements of behaviour	
Blamed		
Insulted by information		

HIV and AIDS information as a moral yardstick		

Experiencing information as spouses	Lived body (selfhood)	Life-world
Experiencing information as carers		
Experiencing information as parents		
Couples or partner as source of information		
Knowledge of the lived body		
Child bearing body		
A vulnerable body		
Personal health information		
Weak body (dying body)		
ART Clinic	Lived space	
Hospital		
Chief's court		
HIV support group		
Church		
Vulnerability		
Stages • Information searching before testing positive • Information searching after testing positive Truncated life span What will happen to me?	Lived time	
Relationships • Church • Spouse • Family • Community Some information is divisive	Lived relations	

Notes:

- Lived time: couples described past, present and future experience of information
- Lived body: Had questions about their child bearing bodies; their bodies as breadwinners
- There is a complex interplay between HIV and AIDS information, traditional beliefs about marriage, and religious values
- There are differences between HIV positive partners and HIV negative partners
  - Some couples had different interpretations of HIV and AIDS information (e.g. #4)

- - Some couples experienced looked for information as a couple while others as individuals
- HIV and AIDS information is used as a defence tool against stigma and discrimination
- The evolving nature of HIV and AIDS information triggers anxiety and distress especially when it communicates new and unfamiliar HIV related conditions and opportunistic infections
- HIV and AIDS information is not regulated. (Read about information standards)
- HIV and AIDS information as a source of knowledge about the lived body (#7)

Appendix XIII: Moustakas' (1994) Modification of Van Kaam approach

The steps are presented in a linear order for clarity. As stated by Van Kaam (1966) the analysis process is iterative, the steps overlap and do not follow a logical order.

1. Listing and preliminary grouping

The researcher uses the transcribed interview of each participant and lists all expressions that are related to the experience (Moustakas, 1994). These expressions are classified into categories to capture predominant features of the phenomenon. The validity of these categories is checked by expert judges (Van Kaam, 1966)

2. Reduction and elimination

The expressions listed in Step 1 are the exact descriptions of the experience as given by the interviewee. The researcher will reduce the listed expressions to remove overlap and vagueness (Van Kaam, 1966). Expressions that do not contain descriptions of the experience that are essential to understanding the phenomenon are eliminated alongside the vague, overlapping and repetitive expressions (Moustakas, 1994). The expressions that remain are called the invariant constituents of the experience. Invariant constituents are "the unique qualities of an experience, those that stand out" (Moustakas, 1994, p. 128).

3. Clustering and thematizing the invariant constituents

In this step, the invariant constituents of experience are clustered according to their thematic similarities and given a label. The clusters form the core themes of the experience (Moustakas, 1994)

4. Final identification of the invariant constituents and themes by application: Validation

The invariant constituents and themes are validated against the experience as recorded in the interview. Moustakas (1994, p. 121) proposes that the researcher should as two questions; "are they expressed explicitly in the complete transcription?", "are they compatible if not explicitly expressed?". Expressions that are not explicitly expressed and not compatible are considered not invariant constituents and therefore deleted.

5. Textural description for individual research participant

The researcher uses the relevant, validated invariant constituents and themes to construct for each research participant a textural description. The textural descriptions should include verbatim

examples from the interview transcripts. Moustakas (1994) states that in textural description all aspects of the experience as given by the person experiencing the phenomenon are included.

6. Structural description for individual research participant

From the textural description, the researcher constructs for each research participant an individual structural description of the experience. While the textural components of the experience concern the "what" of the experience, the structural components concern the "how". This description is at a higher level as the researcher seeks all possible meanings of the experience using imaginative variation.

7. Textural-structural description

The researcher will construct for each research participant a textural-structural description of the meanings and essences of the experience, incorporating the invariant constituents and themes.

Appendix XIV: Colaizzi's (1978) Approach

Colaizzi (1978) states that his approach to analysis of phenomenological data should be viewed as just an example and not definitive. The steps in the process are iterative, flexible and overlap. Colaizzi advises that researchers should start by describing their presuppositions and interrogate these to come up with beliefs, hunches and attitudes about the phenomenon. The beliefs, hunches and attitudes will form the basis for questions that would be used in the interview.

1. Acquiring a sense of each transcript

This step involves reading the interview transcript repeatedly in order to acquire the meaning of the description of the experience.

2. Extracting significant statements

After grasping the sense of the transcript through repeated reading, the researcher extracts phrases and sentences that carry the fundamental meaning of the phenomenon being researched. Sanders (2003) proposes that the phrases and sentences should be copied to another sheet of paper so that they can be read with openness to identify themes.

3. Formulation of meanings

Colaizzi (1978) proposes that when carrying out this step the researcher should make explicit any presuppositions to avoid misinterpretation of the experiences of the research participants. In this step of analysis, the researcher formulates more general statements to represent the meaning of the experience. Here the researcher moves from what the research participants said to what they meant (Colaizzi, 1978).

4. Organising formulated meanings into clusters of themes

After formulating these general statements of meaning of the experience the researcher group the statements into clusters of themes. The themes should be validated by referring back to the original interview transcripts (Colaizzi, 1978).

5. Exhaustively describing the investigated phenomenon

The fifth step involves describing the experience exhaustively using the themes.

6. Describing the fundamental structure of the phenomenon

Following from the exhaustive description, Colaizzi (1978) states that the research should identify and describe the essential structures of the experience.

7.   Returning to the participants

The final step is validation of the analysis. The researcher returns to the research participant for another interview. The interview elicits the research participants' views of the essentials structure and the extent to which they represent their experience of the phenomenon (Colaizzi, 1978).