



# **Experiences of People Living with HIV/AIDS in a Plural Health Care System: Probing Tensions and Complexities**

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## **DEDICATION**

I dedicate this Doctoral thesis to my parents, Mr. Christopher Darong Gajere and Mrs Maria Christopher Gajere, who, despite their financial challenges, taught me immeasurable lessons money cannot buy: the need to believe in God, patience, trust, determination and resilience in all I do. These characteristics became vital points of strength throughout my PhD journey.

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## ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical and Research Foundation
ART	Antiretroviral Therapy
BREC	Biomedical Ethics Research Committee
CAM	Complementary and Alternative Medicine
CD4	Cluster of Differentiation 4
GCP	Good Clinical Practice
GHBN	Global Health Bioethics Network
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
OM	Operational Manager
PLHIV	People Living with HIV
TAM	Traditional African Medicine
TB	Tuberculosis
THP	Traditional Health Practitioners
UKZN	University of KwaZulu-Natal
UNAIDS	Joint United Nations programme on HIV/AIDS
WHO	World Health Organisation



## **ABSTRACT**

HIV/AIDS is treated biomedically. People living with HIV (PLHIV) are expected to strictly adhere to active antiretroviral treatment (ART) prescribed by biomedical health practitioners in order to “progress” on the cascade of care. Poor progression on the cascade of care, however, has been shown to exist amongst PLHIV. The use of multiple health systems – biomedicine, traditional healing and religious healing, known as medical pluralism, has been said to be a contributing factor in the poor adherence to HIV testing and treatment. Some PLHIV, however, have been shown to be in care while practicing medical pluralism. Thus, this study explores the experiences of such PLHIV in their practice of medical pluralism, especially how navigate the systems and treatments utilised.

This study was conducted at the Hlabisa sub-District, a rural area in uMkhanyakude District of KwaZulu-Natal, South Africa, through qualitative ethnography. Eighteen participants were recruited using theoretical and purposive sampling. Nine PLHIV were the primary participants in the study. Of the nine PLHIV, four were also traditional healers. The other nine participants, made up of five biomedical healthcare practitioners, three traditional healers and one faith/religious healer, were the secondary participants.

The study found that the PLHIV in the study consciously made concurrent, parallel or sequential use of plural healthcare for various health conditions when they believed such conditions can best or only be treated using specific health systems. None of the participants sought to “treat” or “cure” HIV using health systems outside biomedicine. The study found that some of the participants refused initiation into ART due to the attitude of the biomedical health practitioners towards the participants’ use of plural health. Primary participants who maintained their ART all reported to have had suppressed viral loads and high CD4 counts. Their health-seeking behaviours can be seen as an expression of their agency. Hence, rather than excluding them from using basic primary health services due to their plural health use, a better understanding and appreciation of their reasons, motivations, and manners of practising medical pluralism is needed. This will aid in the development of health programmes that better cater for their health needs.

**Keywords/phrases:** PLHIV, HIV/AIDS, medical pluralism, plural healthcare, biomedicine, traditional healing, religious healing

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# CHAPTER ONE

## Background and Literature Review

### 1.1 Introduction

Presently, there is still no known cure for HIV/AIDS; however, according to the World Health Organisation (WHO), using “effective antiretroviral (ARV) drugs can control the virus and help prevent transmission so that people with HIV, and those at substantial risk, can enjoy healthy, long and productive lives” (WHO 2017). Hence, WHO strongly recommends that “ART should be initiated among all adults with HIV regardless of WHO clinical stage and at any CD4<sup>1</sup> cell count” (WHO 2015, 24). This, according to WHO, is based on the gathered “evidence and programmatic experience” that continues to “favour earlier initiation of ART because of reduced mortality, morbidity and HIV transmission outcomes” (WHO 2015, 26). This, so far, is the “officially” recommended and supported treatment by global health regulatory bodies and governments for the treatment of HIV/AIDS because, and as stated by Vitoria et al. (2014), “the provision of ART to people living with HIV [/AIDS] (PLHIV) is first and foremost a life-saving intervention in HIV care” (31). PLHIV are currently expected to be immediately initiated in and remain on ART throughout their lives. This acknowledgement of the role of biomedicine and ART in the treatment of HIV amongst PLHIV is done without any intentions to promote or reject any of the three health approaches focused on in this study. However, life-saving benefits are acknowledged of engaging in ART which include a reduction in viral load, increase in CD4 cell count and a generally healthy life. Based on WHO’s 2015 recommendation on starting ART, the achievement of ‘effective’ HIV treatment, which is closely linked to one’s progression on the cascade of care, dedication is expected of PLHIV in utilising only the biomedically recommended treatment procedures and medicines for HIV or during HIV treatment. Such a view is held as it has been stated that the non-use or poor use of ART and the use of multiple health systems<sup>2</sup> can lead to counter drug effects, drop out of care

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<sup>1</sup> CD4, cluster of differentiation, is a type of white blood cell that contributes to the formation of the immune system and its presence or absence indicates the health status of the immune system (Collins 2016).

<sup>2</sup> The concept of health systems may be argued to be the existence of health approaches whose philosophy and ideology towards health and healing, hence, points of departure, are different. With this understanding, biomedicine, traditional healing, faith healing, Ayurveda, etcetera, will each be regarded as compound health systems as each has a peculiar philosophy and ideology from which its understanding and approach to health and illness is rooted and stems. The concept can also be regarded as the different types of health provision within each

amongst PLHIV (Colvin 2014; Govindasamy, Ford and Kranzer 2012; Miskelly 2006; Moshabela et al. 2011; Mugglin et al. 2012; Pantelic et al. 2015; Rosen and Fox 2011).

Despite the stated concerns of the non-use or poor use of ART and caution against the use of plural health care, PLHIV have been shown to continually make use of multiple health approaches for a variety of reasons while on ART (Appelbaum Belisle et al. 2015; Miskelly 2006, Moshabela et al. 2011; Peltzer et al. 2008). This choice to continually make use of multiple health systems can be linked to the difference in what entails “effective” treatment of health conditions in many societies and by many people, regardless of HIV status despite the wide agreement on the understanding of HIV/AIDS and its treatment. Such a difference in the view of what entails “effective” treatment exists primarily because different societies possess and express different understandings and approaches to health, illness and healing or treatment (Naidu 2014; Naidu 2013; Vaughn, Jacquez and Bakar 2009). Thus, this study seeks to understand why and how PLHIV, who make use of plural health care, manage to do so, despite the tensions and complexities associated with such an approach to health-seeking.

Since the 1980s when HIV was first discovered and traced back to Kinshasa, Democratic Republic of Congo (DRC), where it was said to have been in existence since the 1920s (see Faria et al. 2014; Kallings 2008; McClure and Schulz 1989; Sharp and Hahn 2011), great strides have been achieved in combating the disease. These strides include the early days of its discovery and acknowledgement in other communities outside the DRC, notably the United States of America<sup>3</sup> (see Faria et al. 2014; Kallings 2008). The strides in combating HIV/AIDS have been achieved through global-level and country-specific intense awareness campaigns

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compounded system, such as the existence of independent chemists, private doctors, primary health facilities, hospitals, etcetera all falling within the realm of biomedicine (see Moshabela et al. 2011). In the current study, however, the concept of health systems will be understood and used as health approaches with varying points of references for health and healing in terms of their philosophy and ideology towards health and healing. Each of the systems will be seen and treated as a compound health system, while acknowledging the different sections within each.

<sup>3</sup> While HIV had spread beyond the DRC as far back as the 1960s areas such as Haiti, not much attention was given to this rare disease (see Faria et al. 2014). Instead, stigma and discrimination was meted on all infected persons, especially Haitian professionals who made a return from the DRC due to the epidemic. Attention was only given to this epidemic in the early 1980s when health professionals in the United States of America (USA) began battling to handle various infections such as Kaposi’s Sarcoma and Pneumocystis pneumonia (PCP), particularly amongst gay men around New York and California (Friedman-Kien et al. 1981; Hymes et al. 1981). Due to the lack of clarity as to the nature of the epidemic, it was called “gay compromise syndrome” (GCS) (Brennan and Durack 1981) due to its prevalence amongst gay men. However, in 1982, after the realisation that the epidemic was spreading beyond gays to haemophiliacs and heroin users, the disease was named AIDS (Avert 2016; Center for Disease Control (CDC) 1982).



(see Heywood 2009; Kalichman and Simbayi 2003; Maibach, Kreps and Bonaguro 1993; Noar 2006; Palmgreen et al. 2008; Treatment Action Campaign (TAC) 2012), massive rollout of ARVs (see, for example, Butler 2005; Mbali 2004; Naledi, Barron and Schneider 2011; Natrass 2007; Schneider and Stein 2001) and HIV prevention materials, such as condoms and prophylaxes (see Baeten et al. 2012; Pinkerton and Abramson 1997; Pretorius et al. 2010; Van Damme 2012).

This has thus led to a reduction in new infections, high availability and access to ARVs and other treatment services to PLHIV. However, there also remain numerous challenges in combating the epidemic. Notable amongst these challenges are the lower than expected uptake of HIV test and treatment, low retention in the treatment regimen, high drug-resistance and drop out from the cascade of care (see Colvin et al. 2014; Govindasamy et al. 2012; Rosen and Fox 2011; Moshabela et al. 2011; Mugglin et al. 2012; Pantelic et al. 2015). These challenges have thus given rise to concerns about the impact of the existing awareness programmes and the provision of facilities and services in controlling and preventing the spread of HIV/AIDS.

One of the reasons for the supposed setback in utilising HIV control programmes is said to be the practice of medical pluralism (see Miskelly 2006; Moshabela et al. 2011; Mugglin et al. 2012; Pantelic et al. 2015; Rosen and Fox 2011; Saethre 2007). This is especially so in societies, such as rural South Africa, which have multiple health approaches. Medical pluralism has been defined and is generally understood as “diverse ways in which illness can be perceived, understood and treated” (Moshabela et al. 2011, 843); “choice between different kinds of practitioners, between consulting or self-prescribing, and... multiple ways of understanding health and sickness” (Cant and Sharma 1999, 1); and “the coexistence and availability of different ways of perceiving, explaining, and treating illness” (Gilbert 2004, 548). Some of the most common health systems found within the practice of medical pluralism are Chinese medicine, Ayurveda, Traditional African Medicine (TAM), acupuncture and biomedicine (Patwardhan and Mutalik 2014; Stumpf, Shapiro, and Hardy 2008). This thesis thus seeks to explore the experiences of people living with HIV/AIDS (PHIV) in a plural healthcare system, especially, why, when and how they are able to navigate and marry different health approaches, despite the tensions and complexities faced.

## **1.2 The Contestations in the Practice of Medical Pluralism**

Numerous studies have been conducted and literature written on plural health use (see Colvin et al. 2014; Govindasamy et al. 2012; Iroegbu 2005; Moshabela et al. 2011; Mugglin et al. 2012; Neumann 2010; Nyirenda 2015; Pantelic et al. 2015; Rosen and Fox 2011). Some of the studies, such as Moshabela et al. (2011), Neumann (2010), Nyirenda (2015) and Pantelic et al. (2015), highlight the existence of medical pluralism, and flag the practice of this as a negative factor in PLHIV's progression on their cascade of care. The details of what the practice of medical pluralism fully entails, such as when in a person's health journey he/she becomes a plural health user, the reason for such use, manner of use and influencing factors, however, remain scarce and unclear. Researchers have stated that medical pluralism involves the "mixing" of medications, medicines, treatments, and providers (see Gwele 2005; Miskelly 2006; Moshabela et al. 2017; Varga and Veale 1997).

This notion of "mixing", however, creates some ambiguities in the discourse of medical pluralism. This is so because even when the 'what' being mixed is identified, the 'why', 'when' and 'how' such mixing takes place, remains unclear. With low clarity in this process of medical pluralism, medical pluralism will likely continue to be highlighted as a major factor in the failure in the treatment progression of PLHIV. Despite this lack of clarity in how medical pluralism is practised, the concept continues to be used widely in different contexts. The lack of clarity affects how we engage with it in the context of health-seeking behaviours of PLHIV in rural South Africa, especially when the practice among PLHIV is flagged by biomedical health practitioners and researchers (see Moshabela et al. 2011; Neumann 2010; Nyirenda 2015; and Pantelic et al. 2015) as a negative contributor towards 'good' health-seeking behaviours.

Such a view persists despite instances in the past where there appeared some acceptance of medical pluralism and its role in healing and treatments as a functional health approach (see Cosminsky and Scrimshaw 1980; Leslie 1980). More recent studies have also shown a shift from the longstanding fractioning and dichotomisation of healing into different healing systems to a more holistic approach in some societies (see Grace and Higgs 2010; Hughes 2014; Kong 2012; Legrip-Randriambelo and Regnier 2014; Neumann 2010; Shih et al. 2010). In the United States, for example, the government created and funds an initiative, Indian Health Services (HIS), which caters for the health needs of Native Americans in the United States of America. The Native Americans, also known as Indian Americans (Broome and Broome 2007) have a

belief that there is a some connection and synergy between “Mother Earth”, which is the natural environment, “Father Sky”, the “Creator”, “Great Spirit”, Great Mystery”, also known as the “Maker of All Things” (Avery 1991; Broome and Broome 2007; Johnston 2006). Being ill, is thus seen as a disruption between the different beings in the universe. To mend this disruption, however, the “imbalances” in nature ought to be corrected, a role played by the traditional healers. Johnston (2006) states that this process of correction can be a prayer session made up of chants, or the practice of “smudging”, which involves the use of smoke from sacred herbs, which is wave off the negative energies from an ill person, tobacco, ointments, tea, and dances. Hence, maintain high mental, physical and spiritual health, each individual is expected to adhere to prescribed “lifeways” (Avery 1991). Thus, the HIS collaborates with traditional healers on issues such as “Veterans Affairs”, such as *telemental* health (Noe et al. 2014; Shore et al. 2012), behavioural health among the youth (Goodkind 2011) and on general attempts to include the Native Indian community into the health system after being historically excluded from receiving primary health services (Bergman 1999). The sponsorship of this program by the government, displays its openness to the collaborative values of medical pluralism.

Understanding the concept and practice of medical pluralism, especially by PLHIV, will enable us to know why there is either resistance or support for the practice by the different health providers utilised, health institutions, governments and general health users. Hence, this literature chapter unpacks the understandings and use of this concept of medical pluralism. It also explores how this concept is practised by PLHIV in different regions, as shown in literature. Unpacking the concept of medical pluralism serves as a background towards knowing what health systems PLHIV who are plural health users operate in and how this shapes their health life. To achieve this, an extensive scoping review of literature on medical pluralism was conducted. A scoping review has been stated to aim at rapidly mapping “the key concepts underpinning a research area and the main sources and types of evidence available... especially where an area is complex or has not been reviewed comprehensively before” (Mays and Popay 2001, 194).

Guiding the scoping review of this thesis was the conceptual framework set out by Arksey and O’Malley (2005) and the recommendations of Levac, Colquhoun and O’Brien (2010). This approach to gathering literature data addresses broad study scopes through a rapid mapping of key concepts in a study area as opposed to a systematic review which focuses on well-defined questions and study designs identified in advance. Hence, a scoping review seeks to identify the patterns in the use of concepts in a field and in doing so, identify the gaps in such usage and

implications of the usage. Arksey and O'Malley (2005) stated that the scoping review approach to literature review has four main aims: "to examine the extent, range and nature of research activity", "to determine the value of undertaking a full systematic review", to summarise and disseminate research findings" and "to identify research gaps in the existing literature" (Arksey and O'Malley 2005, 6-7). The concept and practice of medical pluralism, which is both complex and less researched, requires such an approach to unpack the concept's use and representation in literature. Also, the discourse on medical pluralism, particularly in relation to PLHIV, is still relatively new and has not been extensively and comprehensively reviewed or researched. Hence, exploring the literature on the practice of medical pluralism solidifies our understanding of how this concept is explained both in literature and by users, and how it shapes the health life of PLHIV. In gaining this understanding, we will be able to grasp not only how the different health systems interact with each other, but also how PLHIV become the centre of the interaction and 'union' of the different health approaches through their use and navigation of the different health approaches. The scoping review also helped in identifying the gaps in the current literature on medical pluralism, especially in the context of HIV/AIDS.

The use of the different systems, especially amongst PLHIV, varies and depends on different factors. The major variances are based on the health-seeking patterns of plural health users, which are often parallel (see Islam 2005; Langlois-Klassen, Kipp and Rubaale 2008), sequential (alternating) (see Langlois-Klassen et al. 2008; Moshabela et al. 2011; Mukolo, Cooil and Victor 2015; Ribera 2007) or concurrent (see Appelbaum et al. 2015; Grant et al. 2013; Moshabela et al. 2011; Saethre 2007; Sibanda, Manimbulu, and Naidoo 2016; Mukolo et al. 2015). As shown, these three patterns have only been discussed in literature either singularly or in pairs. However, I was first exposed to the possibility of all three patterns being found amongst PLHIV using plural health in conversations I had with Prof. Mosa Moshabela in 2015 (conversations with Moshabela 2015). In one of the conversations, Moshabela explained how the already discussed patterns in literature do not fully capture the multiple health-seeking patterns of PLHIV, hence ought to be further explored.

The most dominant health approaches in the understanding of medical pluralism are the following concepts and approaches: traditional healing, Chinese medicine/healing, biomedicine, spiritual healing, acupuncture, Ayurveda, homeopathy and yoga. The three major approaches to be explored in this study, however, are biomedicine,<sup>4</sup> Traditional African

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<sup>4</sup> This is a key term in this study as it is one of the health systems focused on in the study. Allopathic medicine is a broad term for medical (biomedical) practice, also known as Western medicine, 'modern' medicine or 'evidence-

Medicine (TAM),<sup>5</sup> and spiritual, also known as faith healing.<sup>6</sup> They will be the focus of this study, primarily, because they are the most common health systems used in the setting of this study, rural South Africa, but also in many other African communities who share similar health beliefs and practices as shown in Moshabela et al. (2017).

### 1.2.1 Biomedical Healing

Wade and Halligan (2004), in their discussion on biomedical models of illness, asserted that the biomedical approach to health and illness assumes there is always a causal relationship between disease and illness. Disease, in this case, is understood as stated by Brown, Barrett and Padilla (1998, 11), as “the outward, clinical manifestation of altered physical function or infection”; and illness, as stated by Chigona et al. (2008), Naidu (2014), Parle (2003) and Richter (2003), is the total experience and perception a person has of his or her health, a perception and experience often shaped by the individual’s social and cultural views. The conclusion about the difference between health and illness, said Wade and Halligan (2004), is based on two major biomedical assumptions: firstly, that disease (pathology) is *always* the single causal factor of any illness; secondly, that as disease is the causal factor of illnesses, removal of the disease will yield good health. Such a view, says Wade and Halligan (2004, 1398), plays a role in the medicalisation of “commonly experienced anomalous sensations” amongst patients. This view, they said, is a reductionist approach which can be summarised as follows:

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*based*’ medicine. The term ‘allopathy’ was coined in 1810 by a German Physician, Samuel Hahnemann in reference to the usual practice of medicine as opposed to homeopathy. The homeopathic therapeutic system of healing “is based on the concept that disease can be treated with minute doses of drugs thought capable of producing the same symptoms in healthy people as the disease itself” (MedicineNet 2014).

<sup>5</sup> This is one of the key terms in the current study as it is one of the health systems focused on in the study. By Traditional African Medicine, I mean “health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses and maintain well-being” that may or may not be peculiar to African societies, but are practised and dominant in African societies (WHO 2001). This definition is also in line with the WHO’s (2013) definition of traditional medicine which states that traditional medicine is “the sum total of the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness” (13). In this study, the terms Traditional African Medicine and Traditional Medicine will be used interchangeably

<sup>6</sup> The terms ‘faith healing’ and ‘spiritual healing’ will be used in the study interchangeably. Faith healing may be defined as “supernatural healing that results from prayer or the laying on of hands, rather than medicine... that evoke a divine power toward individuals who need healing of a disease or disability” (LaMeaux 2015).

All illness and all symptoms and signs arise from an underlying abnormality within the body, referred to as a disease; all diseases give rise to symptom(s), eventually if not initially, and although other factors may influence the consequences of the disease, they are not related to its development or manifestations; health is the absence of disease; mental phenomena, such as emotional disturbance or delusions, are separate from and unrelated to other disturbances of bodily function; the patient is a victim of circumstances with little or no responsibility for the presence or cause of the illness; the patient is a passive recipient of treatment, although cooperation with treatment is expected. (Wade and Halligan 2004, 1398)

Therefore, persons who may experience or report any form of illness that does not fit into an established biomedical diagnostic routine and become categorised into one form of an already known health condition or express such a potential, are often met with disbelief by biomedical health practitioners. Such an approach has been, to a large extent, maintained in the current implementation of biomedicine as transmitted to different societies through medical globalisation, otherwise known as “biomedical imperialism”, as shown in Finkler (2000) and Macleod and Lewis (1988). Nustad (2003, 7) referred to the process of globalisation as the interaction between “distinct realms of reality”. In this way, both realms play roles in influencing each other. In the case of biomedical globalisation, however, little room has been given for local realms of realities to shape the practice of biomedicine; rather, the practice has been largely enforced on host communities as a “modern” and “safe” approach to health while local practices are regarded as “risky” and “ancient”, hence ought to be discarded.

This approach to health and illness contributes to the regulations on treatments received by PLHIV by governments and world health regulatory bodies. This is so because any other treatments received by PHIV, even if not for treating HIV, are often regarded, mostly by biomedical health practitioners, as “risky”, “dangerous” and/or “unsafe” for the PLHIV. This regulation thus limits the possible role of health approaches used by PLHIV for the diagnoses and treatment of health conditions not treatable by biomedicine. An observation made by Capra in the 1980s, which still persists, is that some biomedical personnel portray a dislocation between the patient’s reality and the patient during diagnoses. Diagnoses are often viewed from the presence of bacteria or physiological disorders in the patient while ignoring their psychosocial context as possible causalities to their illness with patients approached as “body parts” (Capra 1982, 346). While the intentions behind the practice and approach to healing

might have been good, the implementation of the practice, however, seems inconsistent with the approach of a person as a holistic and interconnected being whose well-being can be influenced by any form of disharmony in their cosmic space, not necessarily physiological. Viewing patients as “body parts” has the possibility of detaching health and illness from the patients’ social context, from which such illnesses might have emanated. This is so because the illness experience is both internal to an individual, but also has a strong link to external factors, which may be beyond the understanding and control of the individual or the physician as stated by Naidu and Darong (2015a, 2015b). Gaining knowledge of such possibilities as experienced by patients, which often occurs during close interactions between physicians and patients, according to Vaughn et al. (2009: 64), is important in creating “trust between physicians and patients”. This trust in turn will enable the patients to “accept and follow the medical advice (medical adherence) that will restore or maintain wellness” (ibid.). Failing to carry out such interaction and build trust, however, said Vaughan (1991: 5), “causes those who are ill to feel powerless and alienated”, but also, leads to a lack of progress in their healing.

### **1.2.2 Traditional Healing**

Traditional healing or medicine is sometimes referred to as folk medicine, indigenous medicine/healing or ethnomedicine (see Pordié, 2007; Rhodes et al. 2008; Rubel and Hass 1996; Saijirahu 2009; Weisberg 1984). Although the concept of traditional healing and medicines are sometimes treated separately, they will be used interchangeably in this study to refer to the process of using traditional approaches to healing, including the medicines. The concept of “traditional medicine” is not limited to Traditional African Medicine (TAM). This is because traditional healing is practised in other societies aside from Africa and the term “traditional” is also used in reference to biomedicine in its “unevolved”<sup>7</sup> form. However, in this study, the concept will be used primarily in reference to TAM. Central to this healing system is the belief that illnesses can be biological, psychosocial, but also supernatural (Kale 1995; Moshabela, Zuma and Gaede 2016; Naidu 2013; Naidu and Darong 2015a, 2015b, 2015c; Zuma et al. 2016). As stated by Kale (1995), amongst most South Africans, “disease is a supernatural phenomenon governed by a hierarchy of vital powers beginning with a most powerful deity followed by lesser spiritual entities, ancestral spirits, living persons, animals,

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<sup>7</sup> Although biomedicine is still practised independently of any other health approaches in most societies, over the years, it has, in many societies, moved towards collaborative health delivery with other health approaches by accommodating the health belief systems of such societies and accommodate members of such societies (see Grace and Higgs 2010; Hughes 2014; Kong 2012; Legrip-Randriambelo and Regnier 2014; Neumann 2010; Shih et al.2010; Van Rooyen et al. 2015).

plants, and other objects” (1182). These powers have an ability to interact with each other and in the process, increase or reduce the powers and abilities of a person. When there is disharmony amongst the vital powers, illnesses can be caused and ingredients obtained from animals, plants, and other objects can be used in restoring the diminished powers of the sick person (Kale 1995).

Rubel and Hass (1996) defined ethnomedicine as beliefs and practices that emanated from indigenous cultural developments rather than an external development imposed on a people in the form of ‘modern’ medicine. This approach allows for the view and treatment of an ill person as a whole being as opposed to the biomedical approach which often uses a monolithic approach to individuals as body and mind, a view expressed in Parle (2003) and Truter (2007). The ethnomedical approach is similar to the bio-psychosocial approach to health where an eco-systemic view of health, which is hinged on two basic perspectives, is used. The first perspective views the human person as a whole and complete being whose attributes, even when distinguishable, remain inseparable (Kirsten et al. 2009, 4). This first assumption gives room to the second assumption which holds that healing can and should be approached multi-disciplinarily and multi-dimensionally (Kirsten et al. 2009; Jones et al. 2006). The multi-dimensional factors emphasised here, which are also often highlighted in critical medical anthropology, are economic, political and social factors. These factors shape and influence people’s health and illness experience by either hindering or enhancing health. This belief, that the human person is a whole and complete being and should be treated as such, is similar in other societies that recognise and practise traditional healing in a similar form as understood and practised in South Africa. This view has been similarly expressed in literature by various authors (see Appelbaum et al. 2015; Dessecker 2014; Dhalla et al. 2006; Macintyre et al. 2005). Accepting such an approach to health has led to the development of concepts such as *psychobiology*, as conveyed by Dewsbury (1991) and *holistic bio-psychosocial* model to health and illness, as shown in Jordaan and Jordaan (2000). These ethnomedical views stand in contrast to the Cartesian dualistic view of the human person as body and mind/soul (Copleston 1958; Descartes 1641), and in place promote the bio-psychological view and approach to health and illness.

In South Africa, the belief in extra-biological powers as role players in a person’s health is complemented by the high presence of traditional healing practitioners (THPs) who are readily available, accessible and arguably less costly to provide and access than the ‘formal’ health system of biomedicine. More than two decades ago, it was stated that there were about 200 000



traditional healing practitioners in South Africa (Kale 1995). This estimation was similar in the late 1990s when Pretorius (1999) noted that the country had about 150 000-200 000 practising traditional healers. More recently in KwaZulu-Natal only, the South African province with the highest prevalence of HIV/AIDS in the country and the province where this study is conducted, the presence of traditional healers was estimated to be about 25 000 (Gqaleni 2007). This number is, arguably, the highest in any single province in the country. The high prevalence of traditional healers in the country goes hand in hand with the frequent use of the traditional healing system. Popat et al. (2001), for example, conducted a study on how a local South African herb, *Callepis laureola*, known locally as *impila*, meaning health in isiZulu, is used for stomach aches, infestations from tape worms, impotency, cough and the inducement of fertility. Bye and Dutton (1991) noted that the greatest use of the plant was in its 'protective abilities'; it is believed to be able to ward off evils spirits from those who use it, including protecting unborn children. This herb, however, has been noted in the literature to have led to many cases of hepatic and renal toxicity (see Bye and Dutton 1991; Popat et al. 2002; Steenkamp, Stewart, and Zuckerman 1999; Stewart et al. 1998).

This use was estimated by Kale (1995) to be 80%. He stated that this high use is because "traditional healers are enshrined in the minds of the people and were respected in their community, and they are often its opinion leaders" (1182). These figures may not be exact as some traditional healers are unaccounted for because they do not belong to the official list of registered traditional healers. The estimates show a sharp contrast to the low presence of other health practitioners in the country and the province, especially the biomedical health practitioners. The high prevalence of traditional healers in the country, according to Kale (1995), was opposed to the 25 000 medical doctors practising in the country in the mid-1990s. While this figure is likely to have increased as more people now have access to higher education and funding to study for the medical profession, there continues to be a shortage of biomedical personnel in comparison to the number of people that need medical attention (Coovadia et al. 2009; National Planning Commission 2013).

The use of multiple health systems and services, especially TAM, led to the suggestion of the World Health Organisation (WHO) in the late 1990s for the recognition of the role of traditional healers. It suggested that "social and technical training" be given to traditional healers as a way of promoting their inclusion into primary health care, especially in their respective communities (Felhaber and Mayeng 1997). This suggestion was motivated by the evident presence and people's utilisation of traditional healing. This suggestion was followed by the

formal recognition of traditional healers and their role in primary health care in different countries, but most notably by the South African government and with an introduction of the Traditional Health Practitioners' Bill in 2004. The Bill recognised the “unique circumstances of traditional healers, sets professional and ethical standard for traditional healers” and practitioners as a way of empowering them in their practice (Ross 2007, 17). This was followed by the introduction of the Traditional Healers' Act of 2007 (National Department of Health 2015). Moshabela et al. (2016) noted how different these pieces of legislation in South Africa were to the Witchcraft Act of 1957 which regarded any practice of traditional medicine as “witchcraft” and unlawful, thus prohibiting anyone involved in the practice from doing so, with any contravener facing prosecution by the law. Therefore, the Traditional Health Practitioners' Bill serves as a positive progress in utilising local health knowledge and beliefs in the delivery of health. The bill has been continually developed, taking the views of the healers into consideration, as shown in Moshabela et al. (2016). Nonetheless, since the rise of biomedicine outside Western societies, ethnomedicine, which was the dominant practice in some of such societies, became the most utilised health system in medical pluralism. This use, however, is often seen as complementing biomedicine or being an “alternative” healing approach as shown in literature (Keshet and Popper-Giveon 2013; Mpinga et al. 2013; Rhodes et al. 2008; Stoner 1986; Stuttford et al. 2014).

### **1.2.3 Spiritual Healing**

Spiritual healing, sometimes known as faith or religious healing, is based on the conviction that there is a “supernatural healing that results from prayer or the laying on of hands, rather than medicine... that evoke a divine power toward individuals who need healing of a disease or disability” (LaMeaux 2015). Although Christianity is often strongly linked to religious healing (Arias et al. 2016; Gabasiane 2014), religious healing, however, is wider than just Christian religious healing. As shown by Valenkamp and Van der Walt (2006), traditional African healing, in its nature, involves the spiritual life and belief of users whereby the presence of ancestors' spirits are evoked in healing. Nonetheless, the practice of TAM will be treated as a different system from religious healing in this study, as seekers of faith healing, especially within the South African society, often dichotomise the two approaches. In doing so, they seek spiritual healing from Pentecostal healers while traditional healing is sought from traditional healers.

For instance, in a study conducted by Pawluch, Cain and Gillett (2000) in Canada, prayers were regarded by the participants in the study as of high effect to their healing and well-being. This act of prayer, however, is held in high esteem amongst different belief systems. South Africa has been shown to have a high presence of religious healers who have great command over their followers. The extent of the influence of the preachers on the followers and the faith shown by the followers is often seen in the followers' willingness to obey and carry out whatever actions that are commanded by the preachers. Pentecostals within the South African society are often referred to as "born again" Christians, a term which Garner (2000) claimed, is due to "its adjuncts and proselytism, provokes gentle mocking in society at large with the use of the slightly derogatory Zulu phrase *abasindiswa*, the 'saved'" (51). The Pentecostal Christians resort to charismatic healing has been on the rise in the country. Despite incidences which have been questioned by human right groups as human right abuse and by health practitioners as hazardous to health, this rise and need for healing from charismatic pastors has not been deterred (see, for example, The Citizen 2017a; The Citizen 2017b; BBC News 2016; Vilakazi 2016). Such persistence is based on their belief that there are illnesses whereby the causes of the illnesses are regarded as spiritual in nature, hence need a "spiritual intervention" and only that are only healable "spiritually" (Gabasiane 2014; Niezen 1997; Rozario 2009).

Users of these three approaches to healing, especially faith healing and traditional healing, are regarded as plural health users in this study. This is because they are also believed to use biomedicine, either primarily or as a secondary option in seeking health. This use can be done in parallel, sequentially and concurrently, as shown in the literature (see Appelbaum et al. 2015; Islam 2005; Grant et al. 2013; Langlois-Klassen, Kipp and Rubaale 2008; Moshabela et al. 2011; Mukolo, Cooil and Victor 2015; Ribera 2007; Saethre 2007; Sibanda, Manimbulu and Naidoo 2016) and in conversations with Moshablea (2015). Nonetheless, the faith healing and traditional approaches are often regarded as playing a "complementary" or "alternative" role to biomedicine in healing (Keshet and Popper-Giveon 2013). This deleterious response towards integration can be linked to the tension that has been noted between the health systems, especially biomedicine, and other healing approaches, as stated by Engel (1989), Keshet and Popper-Giveon (2013) and Raaphorst and Houtman (2015).

The development of each of these health approaches shapes how they are understood by people and subsequently how they are used, or people's attitude towards them. The impact of each system, however, depends on the dominant ideology that enlightens and guides the conduct of those who use it. Hence, while these systems are not all the same and have different

understandings of health, they all have an effect on their users. These effects can be positive, but they can also be negative (Dessecker 2014; Grant et al. 2013; Macintyre et al. 2005; Subedi 2003).

The use of these different systems consists of multiple complex layers. This complexity is sometimes traced within the same health system where patients use different levels of care within the system, but it is also traced between multiple health systems where users seek care from different health systems. Portraying this complexity, Moshabela et al. (2011), for example, suggested that medical pluralism can be possibly grouped into different degrees, depending on the level of care, whereby plural health-seeking is traced within a health system. Moshabela et al. (2011) referred to this as the different stages in which a patient seeks care from health providers, either within the same health approach or from multiple health approaches/systems. They stated that participants in their study showed the use of health care facilities and providers at three stages: the initial contact, subsequent contact and the final stage. At each stage, the providers used may be within the same health system, however, the number of health systems and providers used increases with each stage of care.

...the first degree of medical pluralism involved the use of multiple service providers within the Department of Health Services and Self-care... The second degree included those participants who utilized private physicians and chemists in addition to Department of Health Services... Lastly, the third degree of medical pluralism captures all the participants who additionally source for help from *non-formal* sector during the course of their illness... (Moshabela et al. 2011, 486-487).

Noting the different ways in which the idea of medical pluralism can be approached, this study approaches the discussion of medical pluralism as the use of multiple health systems or health approaches. This is so because, while not denying the existence of other views of medical pluralism, a persistent element running through the general definitions of medical pluralism acknowledges it as *the presence and use of different "health systems" and approaches* by people seeking health. Thus, the study explores the practice of medical pluralism amongst PLHIV, who like people with other illnesses, have been shown to continue using multiple health systems aside from biomedicine, which is their primary source of HIV care (Moshabela et al. 2012; Nyirenda 2005; Peltzer et al. 2008; Tugendhaft 2010). The focus of PLHIV is peculiar as their healthcare has been stringent and maintained within biomedicine. Hence,

seeking plural health, regardless of reasons, intensifies the need to understand how such usage is made and its impact on their health journeys.

This availability and co-existence of multiple health systems and approaches, and their subsequent use in health-seeking, has been met with a variety of responses by different people or systems. Reactions, however, usually depend on the health systems in question, the illness, the people involved and location of the experience. These are influential factors as to how medical pluralism is explained and understood. Irrespective of how medical pluralism is explained or understood, the practice faces major reproaches and its proponents and their views are frequently challenged as shown in literature (see Colvin et al. 2014; Govindasamy et al. 2012; Miskelly 2006; Moshabela et al. 2011; Mugglin et al. 2012; Pantelic et al. 2015; Rosen and Fox 2011; Saethre 2007). Some of the possible roles played by different health systems used by PLHIV and other ill people have often led to the call for a mutual existence and collaboration of health systems in South Africa and beyond. Some of these recommendations state that traditional healers should be trained in testing and referrals of PLHIV as a way of aiding the biomedical system in treating PLHIV (Kahn and Kelly 2001; King 2000, 24; King and Homsy 1997; Madiba 2010; Mbatha 2010).

### **1.3 Existing Tensions between Health Approaches**

In the heart of medical pluralism is the merger of different healing approaches at some point of a user's health-seeking journey. This merger occurs despite existing differences in how the different health approaches are constructed and deliver healing or treatment. These differences often lead to tensions between the different health approaches. Entrenched in this tension is the question of the effectiveness of the different health approaches and the effectiveness of combining different approaches, concurrently, sequentially or in parallel.

Irrespective of the manner of combination, the use of the different health systems exists with the backdrop of tensions in and between the different health approaches utilised, thus creating tensions and complexities for users in knowing when and how to use the available systems. Due to the existing tension between the different health approaches, when ill, people may be forced to receive partial or *'harmful'* *'treatments'* and services from inefficient health care providers as providers strive to retain their customers despite their inability to adequately assist the patients (see Peltzer et al. 2008). This act may in the end affect the patients' health directly or indirectly. Another possible effect of these existing pluralistic tensions, as stated by Peltzer et al. (2008) is that patients end up concealing their use of other forms of health care from their

primary health providers, especially physicians, even when such treatments may not be harmful. Hence, even when patients make use of harmful ‘treatments’, their various health providers are unable to render the necessary and timely assistance. While such tensions can be traced to the differences in health and illness fundamentals of the different systems, the tensions may also be due to an inadequate understanding of the different systems, not only by users, but also by health providers. Thus, delving into how the different health care systems understand each other, the treatments they provide and the role they play (and are capable of playing) within the South African health system is relevant to understanding how PLHIV make use of and navigate these systems. This is relevant as the existing tensions contribute to when, why, and how PLHIV make use the systems.

Another reason for the continual tensions, even when they appear to be intertwined at different levels, could be the lack of sufficient ‘evidence’ of the ‘effectiveness’ of not only the prevalent healing approaches in Africa, but also of the effectiveness of their combination with different health systems making up a plural health system. The question of effectiveness or relevance of some health systems has led to the conceptualisation and use of terms such as “alternative”, “additional”, and “complementary”, in reference to some health approaches. The belief is that such systems are of less relevance or efficacy to others, which are promoted as the primary health providers in many societies, including those with other health approaches. The idea of a healing system being viewed as an ‘alternative’, ‘additional’ or ‘complementary’ has been argued as being problematic (see, for example, arguments by Keshet and Popper-Giveon 2013; Mpinga et al. 2013). This is because such a view overlooks the possible independence of each of the health approaches. This independence has, over the years, been derived from such health systems when they would have been the only or main sources of healing for the community in which they exist in. The development of new health approaches, one may argue, would have been regarded as the alternative with the original health approaches in the communities regarded as the main approach. However, due to the hegemony of biomedicine in its spread and practice, health systems of local communities that originally had no knowledge of biomedicine are given little or no value in primary health. Mpinga et al. (2013, 45), for example, stated that “the attributes ‘additional’ or ‘alternative’ translate an epistemological discomfort on the identity of these medicines, which are perceived as complements or alternatives to the *modern medicine*”. In line with Mpinga et al.’s (2013) argument, Keshet and Popper-Giveon (2013) also asserted that these terms, in themselves, “reflect hierarchical divisions and power relations” whereby one form of healing is oppressed and undervalued by the other (369). These

created hierarchies have continued to persist through time despite the historically and currently known, and in some cases accepted, vital role played by the different health approaches in the primary health care of many societies.

Despite the criticism, studies have shown that ‘complementary’ and ‘alternative’ medicine, as they are called, are used by about one third of Americans (Eisenberg et al.1998), one fifth of British (Fulder 1996) and a similar number in the United States and Europe (Eisenberg et al. 1993; Fisher and Ward 1994). Also, TAM as an ethnomedical health approach has been shown to be highly prevalent in Africa, amongst other health approaches, and its usage strongly regarded as ‘alternative’ healing (Appelbaum et al. 2015; Grant et al. 2013; Hughes 2014; Iroegbu 2005; Peltzer et al. 2008). This usage has continued to persist despite the negative attitude often shown towards it, especially with the advent of biomedicine. This persistence is due to the strong belief users of TAM have in the system, thus influencing how they adhere to what they may regard as foreign.

Critics of TAM being used with biomedicine have placed more emphasis on differences that have been regarded as the ‘limitedness’ of the practice and its ‘shortcomings’. Some differences are the possible toxicity of medications – herbs – due to the absence of standard measurements or the inexplicability of some diagnoses, which are more spiritual than empirical (see, for example Popat et al. 2001; Stewart et al.1999; Stewart, Steenkamp and Zuckerman 1998; Thomson 2000; Venter and Joubert 1988). Most of the differences have emanated from a side-by-side comparison of TAM with biomedicine, which operates strictly based on universal standards that are always expected to be empirical. Such emphases are made while almost totally ignoring the persistent value and relevance of TAM with its difference in approach to illness and health.

Proponents of TAM and other non-biomedical healing approaches have continued to express the need for the integration of the multiple healing approaches into the ‘mainstream’ healing process by creating room for mutual complementarity as they are often able to play roles that one approach on its own is unable to play (see Adler 2002; Aginam 2007; Ben-Arye et al. 2013; Hughes and Mbamalu 2015; Kong 2012; Patwardhan and Mutalik 2014; Templeman Robinson 2011). Having this view places the different healing systems as complementary to each other in providing holistic health in different scenarios and times rather than one being complementary and the other a mainstream approach. Some authors (see Feierman and Janzen

1992; Tilley 2011; Vaughan 1991) have argued for the non-existence of a difference between the different health approaches, especially biomedicine and ethnomedicine, claiming that they all have the same origin but their current forms are applied differently based on the ideologies of the practitioners. While that argument may seem plausible, its rightfulness may be questioned as the understanding of effectiveness differs between the different healing approaches. These differences in effectiveness, which are achieved through the deliverance of treatment, administration of medication/herbs or a healing ritual/process, are fundamental in the existing difference between the health approaches. Borrowing from Etkin's (1988, 300) definition, effectiveness can be generally agreed to, irrespective of medical ideologies, mean a "combination of symptom reduction and other physical and behavioural transformations that indicate restoration of health".

Understanding and valuing the effectiveness of a healing approach, however, especially one that does not operate on empirical evidence or universal standards can be challenging. This is so because verifying and determining the effectiveness of an approach can be either from an emic or etic point of view. While an emic perspective is culture-specific and in line with the ideologies of the society in question, an etic perspective makes use of concepts and theories from ideologies other than those of the studied society or healing system as a framework and yardstick for understanding and measuring effectiveness (Etkin 1988, 300). Having these two possible perspectives in mind is important while attempting to understand and avoiding generalising the notion of effectiveness. This is because such generalisation "obscures a wealth of meanings and expectations that are encoded within the complex patterns of medical behaviours that characterize different medical systems" (Etkin 1988, 300). Therefore, understanding the effectiveness of each of the healing approaches used in plural health, individually or in combination with other healing approaches, is vital towards understanding the roles of such approaches in the practice of medical pluralism. It can be argued that the difference in views regarding health, illness and healing between the different health systems is relied upon to regard one approach as efficacious and the others as non-efficacious. However, what is held and understood as effectiveness in biomedicine, for example, is not necessarily understood the same way in TAM or faith healing, despite the general fluidity of effectiveness in all health approaches.

In biomedicine, for example, the fluidity of effectiveness is not very common as most diagnoses and treatment to an illness or health situation remain almost constant, irrespective of person or



location. Although a diagnosis and treatment approach may change over time to tackle mutating or resistant viruses, this change, however, is often applied to all persons and locations where such a viral mutation or resistance is detected. In the case of HIV/AIDS, for example, diagnoses, medications and treatments have been changed over time as new strands of the HIV virus are detected and existing viruses mutate and become resistant to the already developed treatment (see Faria 2014; Flexner 2007; McClure and Schulz 1989; Sharp and Hahn 2011). Despite developments in the discovery and production of new biomedical treatments for different health conditions, there can be cases of misdiagnosis or the prescription of wrong treatments and medications (see, for example, Berner and Graber 2008; Rusnak, Borer and Fastow 1994; Weingart et al. 2000), which can be linked to the health providers' negligence. Such a wrong prescription or diagnosis can lead to adverse effects on patients. However, the few cases of wrong diagnosis or wrong prescription do not necessarily make biomedicine, as a practice, 'ineffective' or 'harmful'. This is because such incidences may only be coincidental or accidental. Even when the appropriate treatment is prescribed, as has been shown (see, for example, Classen et al. 1997; Edwards and Aronson 2000; Forster et al. 2003), some individuals react negatively to some treatments, despite such treatments being the generally-prescribed treatments for similar health conditions in others. Such cases are often referred to as deviant cases or 'adverse events'. More so, proponents of biomedicine will argue that its effectiveness has been proven over the years; hence, a few mishaps cannot give rise to the questioning of its effectiveness as a health approach. Why then, one may ask, do instances of adverse effects in the use of plural health or health approaches other than biomedicine warrant the immediate questioning of their effectiveness?

In ethnomedicine, effectiveness can be as fluid as the number of patients seen by a healer in a day. This is so because, often, medicines or healing approaches in this system are uniquely tailored based on the individuals needing healing. This individually tailored delivery of health has also been noted in literature (see De Villiers 2006; Grant et al. 2013; Waldram 2000). In this approach, the patient's familial and personal experiences are taken into consideration, including the state of their relationship with community members, dead or alive. However, some may argue that biomedicine also takes consideration of patients' particular medical history and conditions before administering a healing procedure. That however, is still conducted within an almost universally prescribed, understood, hence followed procedure whereby a clinician already has a variety of prescribed approaches for any noticed change needed for patients' unique situations. With ethnomedicine, however, there exist no universal medical combinations or a combination of 'procedures' that could or should be followed by a

healer. As stated by Golooba-Mutebi and Tollman (2007a), healers are able to identify patients' unique situations and from there are 'informed' of the procedure or medicine needed for such a patient by the ancestors. Therefore, the same health condition experienced by two individuals may have completely different medicines or healing process prescribed.

Regardless of the existing tensions between the different health systems utilised by PLHIV, they have been shown to be able to 'resolve' the tension through certain strategies that allow them to make use of the different health approaches. Medical pluralism can be viewed from the types of illnesses that prompt the switch and change of health approaches. With the understanding of medical pluralism based on an illness, the illness becomes the point of departure towards different health systems. From available literature, the most researched health conditions involving medical pluralism are: HIV/AIDS (Moshabela et al. 2012; Nyirenda 2005; Peltzer et al. 2008; Tugendhaft 2010); mental illness (Callan 2005; Kajawu et al. 2016; Teuton, Dowrick and Bentall 2007); diabetes (Aikins 2002; Kolling, Winkley and von Deden 2010); cancer (Ben-Arye et al. 2013; Broom, Doron and Tovey 2009); and pain management (Brown 2010; Pan et al. 2013). The practice, impact and acceptance of medical pluralism, however, vary from one health condition to another. This is so because illnesses vary in complexity and effect on the human person. While some illnesses may accommodate a variety of treatment regimens with little or no adverse reactions, others may not. Hence, in some illnesses, individuals are able to make use of multiple health approaches through a variety of patterns. HIV/AIDS has been noted as one of the illnesses that people are completely discouraged from engaging in any forms of treatment aside from the officially recommended biomedical treatment. Such discouragement is not only targeted at those who may intend to use other healing approaches to treat HIV, but also to those carriers who may wish to use other health approaches for treating different health conditions. Some PLHIV, however, have been shown to make use of different health approaches in an integrated manner.

Concepts such as plural health, integrative medicine/healing and medical pluralism are used in explaining and building an umbrella over different health approaches when brought together through usage by health-seekers. Such an approach is embedded in studies that seek to explain this concept from the culmination of different health approaches before regarding the combination as plural health care (see Appelbaum et al. 2015; Grace and Higgs 2010; Hughes 2014; Kong 2012; Moshabela et al. 2011; Moshabela et al. 2016; Pantelic et al. 2015; Saethre 2007; Neumann 2010; Shih et al. 2010; Templeman and Robinson 2011). Templeman and

Robinson (2011), for example, stated that the concept of an ‘integrated’ or ‘integrative’ medicine comes “as a result of attempts to explore new ways of conventional medicine and CAM [complementary and alternative medicine] working together” (85). In the same vein as Templeman and Robinson (2011), Neumann (2010) also showed an understanding of medical pluralism as the combination of “herbal and modern medicine” (2). She stated that “current Mayan<sup>8</sup> medical practices are actually an integration of *modern* and *ancient* medicine. Because of this, medical pluralism gives the Maya the security of biomedicine while allowing them to retain continued access to their cultural medical practices” (Neumann 2010, 3). This sort of combination allows a person to make use of dual or more health systems through different patterns. These patterns are the parallel, sequential and concurrent patterns. Hence, the integration that takes place in medical pluralism is made through the combination of different health systems such as Chinese medicine, in combination with Ayurveda, Ayurveda with TAM, acupuncture and biomedicine, etcetera (Patwardhan and Mutalik (2014; Stumpf, Shapiro, and Hardy (2008). This combination can be between or amongst any of the different health approaches using the different possible plural health-seeking patterns.

These patterns further display the complexity in medical pluralism and they are alluded to in literature as health-seeking patterns of participants in studies such as Appelbaum et al. (2015), Grant et al. (2013), Islam (2005), Moshabela et al. (2011), Saethre (2007), Sibanda et al. (2016), and Mukolo et al. (2015), Moshabela et al. (2011, 847), in reference to the patterns of plural health-seeking identified amongst participants in their study, stated:

Two types of pluralism were predominant amongst those showing variations in the sources of health care for their illnesses ... participants showed a sequential pattern of use,<sup>9</sup> whereby participants visited different service providers in succession without returning to the previous one. ...concurrency was identified among those who tended to see different providers over the same period of time.

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<sup>8</sup> These are members of a rural community in Guatemala where Neumann’s (2010) study was conducted.

<sup>9</sup> Also referred to as ‘alternative plural health-seeking’ in this and other studies (see for example, Cassidy 1998; Ennis 2014; Gilbert 2004; Peltzer et al. 2008).

Their study alluded to two patterns of medical pluralism discovered amongst the study participants, alternative (sequential) and concurrent usage. Sequential plural health users are those users who use different health systems alternatively, either for the same or different illnesses and symptoms, but at different times. Concurrent plural health users, on the other hand, have been shown to be users who make use of different health systems for the same health condition, illness or symptoms at the same time. In a study conducted amongst the Aboriginals, Saethre (2007) showed how some of the participants in the study, whom he named Sarah and George, sought health for their different illnesses. Noting the existence of local approaches to health and the existence of biomedicine in their community, Sarah and George, like many other Aboriginals, said Saethre, made use of plural health concurrently or exclusively. He said:

Regardless of whether or not the clinic was initially consulted, George and Sarah both took a variety of biomedical drugs for the duration of each of their illness episodes. While George attributed his illness to sorcery, he regularly took paracetamol and requested antibiotics. Even when healthy, George consumed paracetamol so often that he always kept a pack in his pocket. Sarah was prescribed medication by the clinic and even after she began consulting *ngangkari* – an Aboriginal healer, she continued to take the pills sporadically, as well as paracetamol. (Saethre 2007, 104)

Interesting in the case was that while one participant had the belief that his illness was traditional, he found the need to make use of biomedicine for the headaches he was experiencing due to what he regarded as sorcery. So too with Sarah, even though she had been to the clinic for her headaches, she still saw the need to ‘double up’ the treatment by visiting a local traditional healer. These practices are similar in different contexts and are familiar to concurrent plural health users. While they may seek health care from different health providers and approaches for the same health conditions, they may also do so for different aspects of the same condition. This belief in the need to ‘double up’ one’s treatment, said Saethre, was “because the diagnosis of an illness episode can shift and does not solely influence treatment seeking, local aetiological beliefs should not be viewed as invariably detrimental to the adoption of biomedical therapies” (106); neither should local conceptions of health “be automatically reduced to a single or rigid Aboriginal system that is contrasted with biomedicine” (108) despite its influence on how biomedicine is conceived and treated within the Aboriginal society.

The concurrent use of plural health, although not widely so, was also highlighted by Appelbaum et al. (2015) in their study of the concurrent use of TAM and biomedicine by PLHIV in South Africa. They stated that while one of the participants in the study, although not a concurrent user, asserted the use of TAM and ART concurrently was acceptable, so too did other participants who expressed a desire and willingness to be concurrent plural health users. One of the participants in the study was a concurrent user who used TAM to treat HIV while also being on ART. According to Appelbaum et al. (2015), the patient had been a user of TAM long before her diagnosis with HIV; thus, she continued her use of the healing approach concurrently while on ART because “TAM was part of her Zulu heritage that she is proud of and she believed that it ‘brings [her] health’ to use both TAM and ART concurrently” (2015, 79).

In the same study, however, Appelbaum et al. noted that some of the participants expressed a variety of reasons for using TAM while on ART. Many reasons, they said, were not related to HIV. Some of such reasons included using TAM to gain success in business and sexual prowess, amongst others. They said, “some of the participants remarked that continuing to use TAM after beginning treatment is irresponsible”, a view Appelbaum et al. regarded as “indicating knowledge among the patients in this study of the effectiveness of ART for treating HIV” (2015, 77). Such usage is what is regarded as parallel plural health use, whereby users of plural health care make use of multiple systems simultaneously to treat different health conditions, not even symptoms of the same condition as could be found in concurrent usage (Grant et al. 2013). The parallel use of the two health systems has also been written about by Islam (2005) as practised amongst the Philippines with participants displaying similar parallel plural health-use and reasons for such usage as found in Appelbaum et al. (2015). These three categories of plural health users can be found in different settings and illness experiences.

The different possibilities in use of health systems place users within a complex system that can be to their benefit but also can bring more difficulties to their healing process as shown in literature (see Barker et al. 2006; Moshabela et al. 2011; Moshabela et al. 2012; Moshabela et al. 2016; Van Rooyen et al. 2015; Wreford 2005). It is within this plural context, however, that HIV/AIDS and other illnesses exist. Hence, even when noted in literature, the implications of the different patterns of seeking plural health are not clearly stated. Instead, different studies have made individual references to the different patterns without providing much detail of how those patterns are developed, differ, are maintained and affect the health progression of its

users. In contributing to unpacking the concept and practice of medical pluralism, the different characteristics of each plural healthcare pattern are teased out in this study. Teasing out the plural health-seeking characteristics of each pattern is critical, as this study shows that each pattern has its unique way of playing out while users traverse the plural health system and so too are the reasons and implications for using each pattern.

#### **1.4 Current HIV Burden**

The prevalence of people living with HIV globally in 2016 as stated by the Joint United Nations Programme on HIV/AIDS's (UNAIDS) Global Statistics' Fact Sheet on HIV/AIDS (2017) is 36.7 million [34.0 million – 39.8 million]. Of this number, 5.1 [3.9 million – 7.2 million] are from Asia and the Pacific; 1.6 million [1.4 million – 1.7 million] from Eastern Europe and central Asia; 1.8 million [1.4 million – 2.1 million] from Latin America; 310,000 [280,000 – 350,000] from the Caribbean; 2.1 million [2 million – 2.3 million] from western and central Europe and North America; 230,000 [160,000 – 380,000] from Middle East and North Africa; 6.1 million [4.9 million – 7.6 million] in western and central Africa; and 19 million [17.8 million – 21.1 million] from eastern and southern Africa (UNAIDS 2017). New infections have continued to be recorded each year, although at a lesser rate than in previous decades and the early days of the HIV breakout (UNAIDS 2011). The UNAIDS Global AIDS Update shows that in 2016, 1.8 million [1.6 million – 2.1 million] people became newly infected with HIV (UNAIDS 2017, 1). This is a massive 20% decrease of new infections as compared to the 2.2 million [2 million – 2.5 million] new infections of 2010 (UNAIDS 2011).

This trend is not different in South Africa, a country with the highest number of PLHIV and ARV treatment globally. In the early 2000s the HIV prevalence in the country was said to be between 11.4 percent and 20.1 percent in the overall population (Hunter 2003, 689; Shisana and Simbayi 2002; World Health Organisation (WHO), United Nations Office on Drugs and Crime (UNODC) and Joint United Nations Programme on HIV/AIDS (UNAIDS) 2004). Within a period of 15 years, 1990 - 2005, the HIV prevalence rate in the country soared from less than 1% to around 29% (Hunter 2003, 689). More than a decade ago, WHO reported that there were 1 600 new cases of HIV infections reported every day in South Africa (WHO, UNODC and UNAIDS 2004). This meant that there were approximately 584 000 new infections every year in the country. Since then, Statistics South Africa (2016, 6) has shown showed that, the number of PLHIV in the country has increased from 4.72 million in 2002 to 7.03 million in 2016. This makes a total of 12.7% of the overall South African population,

although the yearly infection rate has declined from 1.77% in 2002 to 1.27% in 2016 (Statistics South Africa 2016, 6).

Despite the high prevalence and the yearly recorded new infections, there have been robust campaigns aimed at controlling and combating the epidemic, particularly increasing availability and accessibility of ARVs. There has been a significant increase in the number of people who now have access to ARVs and a rise in viral suppression amongst ARV users (Granich et al. 2010; Levi et al. 2016; Vitoria et al. 2014). According to the UNAIDS 2017's Factsheet of Global Statistics on HIV/AIDS, 19.5 million PLHIV had access to ARVs globally as at December 2016 (UNAIDS 2017, 1). This is an increase "from 15.8 million in June 2015 and 7.5 million in 2010" (UNAIDS 2016a, 1). This increase is almost 5 million higher than the 2015 target set by the United Nations General Assembly in 2011 (UNAIDS 2016b, 1). This increase in ARV access is also well noted in Africa such as in eastern and southern Africa where "six out of 10 people on antiretroviral therapy" globally live; about 11.7 million were on ART at the end of 2016 (UNAIDS 2017, 2). This is about 60% [48 – 68%] of all PLHIV in the region. Such a high ART programme can be noted when as at 2016, the UNAIDS' Global AIDS Update (2016b, 3) stated that "South Africa alone has nearly 3.4 million people on (ARV) treatment, more than any other country in the world".

In Middle East and North Africa, treatment coverage was registered to be 24% [15-41%] in 2016 (5). Likewise in western and central Africa, 2.1 million people were accessing antiretroviral therapy, 35% [24–44%] of PLHIV in the region (3). All these statistics present a high increase in access to treatment for PLHIV, both globally and in Africa as a continent. With the continuous increase in the number of PLHIV in the country also comes a much-needed increase in the ARV access programme and other intervention programmes.

### **1.5 HIV Treatment-seeking and Adherence**

Despite the high availability of ARVs and the treatment support available for PLHIV, there continues to be a high rate of new infections, slow uptake of treatment, poor retention in care, slow progression in viral suppression due to non-adherence and untimely death, along the HIV cascade (Bezabhe et al. 2014; Colvin et al. 2014; Govindasamy et al. 2012; Nyasulu 2016; Mugglin et al. 2012; Rosen and Fox 2011). The key to a successful progression on the cascade of care is said to be strict adherence to biomedical treatment. The importance of this adherence has been emphasised by different studies, especially its role in preventing drug-resistance and

cross infection (Moshabela et al. 2011; Paterson et al. 2000; Wainberg and Friedland 1998). Adherence, per se, has been defined as “the act of conforming to the recommendations made by the provider with respect to timing, dosage, and frequency of medication taking” (Cramer et al. 2008, 44). To yield a positive outcome in a person’s progression in the HIV care cascade, Bezabhe et al. (2014) asserted that there has to be at least 95% adherence from the ‘patient’. This, they claim, will “prevent the development of resistant viral strains” (1). Non-adherence, on the other hand, “may result in regimen failure, immune suppression, and emergence of resistant viral strains, limited future treatment options, and higher treatment cost” (1). The lack of adherence has been noted in a study in Ethiopia where the progression of 3012 adult HIV patients on the cascade of care was tracked over a period of five years from when they were enrolled in therapy at a university hospital. At the end of the fifth year, it was reported that 31.4% of the patients had been lost to follow-up (Wubshet et al. 2012). In some instances, the poor adherence has been said to have led to an increase in mortality.

Previously, the increase in number of PLHIV and the poor state of health services and awareness on HIV/AIDS led to the sharp increase in mortality, especially in less resourced countries. In South Africa, for example, the life expectancy of an average adult has decreased by 10 years (Naledi et al. 2011, 18). The mortality rate in the country increased from the recorded 381 820 in 1994 to 579 709 in 1999, most of these occurring amongst the population aged between 20-50 years and the major cause for the addition was attributed to HIV (Statistics South Africa 2012). UNAIDS (2008) also reported that as of 2008, about 25 million people had died of the disease globally, an increase in the number of deaths from 20 million in 2007. These deaths are often either ascribed to poor utilisation of available HIV programmes and services or poor implementation. Recently, however, due to the increase in access to ARVs, prevention of mother to child transmission (PMTCT) and other HIV programmes, there has been a massive decrease in deaths, globally, and in African countries, including South Africa. The UNAIDS Global Statistics on HIV/AIDS shows that in 2016, “1 million [940 – 1.3 million] people died from AIDS-related illnesses worldwide compared to 1.9 million [1.7 – 2.2 million] in 2005 and 1.5 million [1.3 – 1.7 million] in 2010” (UNAIDS 2017: 1). This is a decrease by 43%” (UNAIDS 2016b: 1) globally, and by 38% in eastern and southern Africa since 2010 (UNAIDS 2017, 1).

On a global level, medical pluralism has been featured as one of the characteristics of PLHIV in their treatment-seeking, regardless of the illness the treatment is being sought for. The practice of medical pluralism can be based on the health approaches used or based on the illness



for which healing is sought. However, the geographical location and people involved in the practice, have also shown to be influential factors in how medical pluralism is explained, understood, and should be understood.

So much has been written globally on medical pluralism as the use of multiple health care systems by people in different health, cultural and geographical contexts, mostly not in relation to HIV/AIDS (see Broom et al. 2009; Callan 2005; Cant and Sharma 1999; Cosminsky and Scrimshaw 1980; Dessecker 2014; Gilbert 2004; Kolling et al. 2010; Kong 2012; Leslie 1980; Macintyre et al. 2005; Moshabela et al. 2011; Neumann 2010; Nyirenda 2005; Saethre 2007; Shih et al. 2010; Stevenson et al. 2003; Subedi 2003; Tugendhaft 2010). Only few studies within the global context are directed towards understanding the relation of medical pluralism to HIV/AIDS. In the few instances where such a relation is sought, the identification of medical pluralism as a negative factor in the health-seeking behaviours of PLHIV is the most highlighted view. Not much attention is placed on understanding the dynamics involved in this use of health systems.

One of such few studies was conducted by Micollier (2004) where she sought to understand the socio-cultural aspects of the HIV epidemic in China, a country which has some of the most practised and documented plural health-use across health conditions. Micollier noted that “most people still have great faith in the idea that STDs – sexually transmitted diseases – and AIDS can be cured by traditional and popular medicines” (2004, 18). This may be partly linked to the availability and high use of both traditional Chinese medicines and biomedicine within and outside the institutional health framework, but also due to the general health beliefs of the health seekers. The availability and accessibility of the different health systems in combination with different belief systems makes the use of medical pluralism “easy” for PLHIV in China, she said. For example, she noted that the belief in many Chinese communities that medication from the Chinese pharmacopoeia (*zhongyao*), which is one of the most common forms of traditional Chinese medicines, has the ability to “prevent AIDS and STDs by killing HIV, as well as other viruses and pathogenic agents responsible for STDs” (Micollier 2004, 17). Therefore, she suggested that taking note of the local practices and health beliefs is paramount in building AIDS campaigns (19).

In another study in Canada by Pawluch, Cain and Gillett (2000), the meanings attached to ‘complementary therapy’ usage by ‘lay’ PLHIV, was explored. Their understanding of a lay person was “one who is active and critical, who has his or her own complex system of ideas

about health and its maintenance and illness and its management, who manages their own health requirements, and who is *discriminating* in their use of *professional medical* advice and expertise” (Pawluch et al. 2000, 252). Their exploration of the meanings the participants had in using plural health system covered why the participants used the healings systems they use, and how the reason(s) relate(s) to their HIV status. The healing systems used by participants in this study included “traditional native herbal remedies, sweat lodges, smudge pots, drumming and consultation with Aboriginal healers”. Some of the PLHIV “often incorporated particular foods, spices and remedies such as boiled tamarin leaves or lemon grass into their treatment regimens”. Other participants “saw prayer and spirituality as an essential part of their health care strategy” (Pawluch et al. 2000: 254). The research showed that participants’ attached concepts such as “health maintenance strategy”; “healing”; “alternative to Western medicine”; “mitigating side-effects of drugs”; “a strategy for maximizing quality of life”; “coping strategy”; and “resistance” to their use of plural healthcare. The findings of this study and its portrayal of participants practising medical pluralism is similar to other studies also conducted in Canada.

In another study in Ontario with 2 400 participants, 81% of the participants reported the use of “complementary” therapies as at the time of the study or previously, as treatment for their HIV/AIDS. On the other hand, 73.6% reported using treatment systems different from biomedicine to treat their HIV/AIDS related illnesses (Robinson 1998). Of the second category of participants, there are likelihoods that while they might have previously dismissed the use of biomedical treatment for HIV/AIDS and only used other treatment processes exclusively, their subsequent use of the biomedical system for HIV/AIDS and use of other health systems for HIV related illness is more in line with the dominant plural health care patterns in the country (Ostrow et al. 1997).

In the studies above, medical pluralism, as explained in the contexts of each of the studies, was treated with suspicion, and often regarded as a negative factor to the health-seeking behaviours of PLHIV. That might not be surprising as in some of the studies, the participants showed negativity towards the biomedical health system which they were meant to receive their ART from, and in some cases, did not make use of it; instead, they used the “alternative” and “complementary” systems. This approach can be said to be rooted in the ideology of the participants who “describe Western medicine as ‘dangerous’, ‘powerful’ and ‘toxic’ in contrast to non-Western therapies that were seen as ‘gentler’, ‘harmless’, ‘less invasive’ and ‘non-

toxic'. It was in Western medicine that they were more likely to see themselves as 'taking a risk' (Pawluch et al. 2000, 257) as opposed to their use of non-western health approaches.

Within Africa, there have been numerous studies conducted on medical pluralism within the context of HIV/AIDS and other health conditions (see, for example Abdalla 1997; Dhalla et al. 2006; Nyirenda 2005; Oyebola 1986; Tocco 2010; Wiwanitkit 2003). While this can be in relation to the high prevalence and acceptance of health systems other than the biomedical health system in the continent, it can also be due to the supposedly "negative" effect of the practice in Africa based on the supposed "toxicity" of its medicines and "lack of standardisation". In most traditional African societies, there is a belief in a strong cosmological and hierarchical bond that exists between all beings in the universe (Parle 2003; Truter 2007). According to Truter (2007), the hierarchical order is arranged as follows: a ruling deity, lesser powerful spiritual entities, ancestral spirits, living persons, animals, plants and other objects. Thus, amongst many Africans, there is an attribution of illness to a spiritual or social cause whereby a person can be made ill by another through witchcraft and sorcery and not only physiological or biological means (see Dhalla et al. 2006; London et al. 2003; Naidu 2013; Naidu and Darong 2015b; Tocco 2010; Wiwanitkit 2003). This notion of a spiritual connection displays the role of the bio-psychosocial model of health amongst many Africans. As stated by Naidu and Darong (2015b, 232), the "belief in some supernatural or metaphysical being has proven to have a great influence on people's ways of life and attitude towards life". This view and belief extends to people's attitude towards health, illness and healing. Such beliefs, as also shown in studies conducted outside South Africa (see Dhalla et al. 2006; Wiwanitkit 2003), have led to the high use of plural health amongst health-seekers, including PLHIV. Some of these studies have suggested that PLHIV make use of plural health at a higher rate than people with other "serious" illnesses due to their "vulnerability" (Wiwanitkit 2003, 40). Such higher use of plural health care, is sometimes linked to the fear of contracting multiple opportunistic infection by PLHIV due to their high viral load and low CD4 count, which leaves them vulnerable and susceptible to opportunistic infections; thus, seek plural health care to curb the rise and or spread of such illnesses in their systems (see, for example, Attia, et al. 2009; Kalichman, Pellowski and Turner 2011). Aside from this supposed "biological vulnerability", PLHIV are also said to be 'vulnerable' to stigma (see, for example, Gordillo, et al. 2009; Liamputtong, Haritavorn and Kiatying-Angsulee 2009; Miller and Rubin 2007; Skinner and Mfecane 2004), thus, seeking plural health is seen as part of their ploy to avoid the stigma attached to being HIV positive.

In Northern Nigeria “patients frequently ‘shop around’ from among different healing options in attempts to find affordable solutions to their problems” (Oyebola 1986). In a study conducted in the same region, which is predominantly Islamic, Tocco (2010) stated that the cultural and religious dynamics of the society were highlighted in relation to the use of the limited HIV services in the region. He stated that “over the last decade, classical Islamic modes of healing – with their focus on the spiritual dimensions of illness, the power of prayer and Quranic recitation, and the natural cures proscribed in the Quran and the *hadith*<sup>9</sup> have increased dramatically in prominence” (Tocco, 288).

Peculiar amongst such techniques is the presence of group of healing approaches known as ‘prophetic medicine’. This is made up of what he calls, ‘Islamic chemists’ where *material medica* – natural mineral treatments – proscribed in the Quran and *hadith* are made available to the public by religious scholars known as *malamai*, who make use of the Quran and other Islamic texts in dealing with illnesses, both physically and spiritually (Tocco 2010, 388). . The healers are visited by PLHIV who seek healing from them and the healers make use of two prominent processes in treating their patients. The first is the *rukiyya* – a process whereby “passages from the Quran, renowned for their healing powers, are loudly read, either in person or through the medium of tape recording, into the ear of the afflicted person” (Tocco 2010, 288). O’Brien (2001, 225) noted that this practice has been institutionalised into the clinics whereby standard fees are made and specific outcomes are expected for each patient’s illness when a specific procedure is followed. This process is claimed to have the ability of curing HIV/AIDS by some of the healers, especially if the cause of the illness is linked to *mugun aljani* – evil spirits. The second approach used by the *malamai* is the *shan rubutu* – literally meaning drinking of writing in Hausa<sup>10</sup> (Tocco, 2010, 299). In this approach, selected passages of the Quran are soaked in water and the water is given to the patient to drink in order to be healed. Abdalla (1997) stated in his study that this use of plural health in northern Nigeria is made by health seekers regardless of their economic status or level of education. He stated that “there are many [of the educated people] who see no contradiction in consulting a traditional [health] practitioner in the evening and seeing a Western-trained physician in the morning” (Abdalla, 30).

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<sup>10</sup> In this process, verses from the Quran are written using a non-toxic ink on a paper. The paper is then washed in water and the sick person drinks the liquid in order to internalise the potency contained in the verse or verses (Tocco 2010, 299). It has been asserted that this use of verses from the Quran for medical purposes, recited or ingested, are acts of piety or devotion “aimed at providing succour or comfort for the sick” (Wall 1988, 237).

Another African country where medical pluralism is reported is Zambia (see Berman et al. 1995; Ndubani and Höjer 1999; Nyirenda 2005). Like in other African societies, the plural healthcare in Zambia is made up of the most common health systems, biomedicine and TAM (Nyirenda 2005). While these systems are different, Nyirenda asserted that they share an interrelation, which is brought together in the users of the different systems. This usage, which can be carried out concurrently, is often carried out alternatively, whereby one system replaces the other in a health-seeking quest (Nyirenda 2005).

This use of plural healthcare in these African communities has often, and in some cases rightly so, been blamed for delays in seeking treatment, poor adherence or eventual drop out from care. For example, in a study conducted at Iringa in Tanzania, most participants in the study were shown to only approach biomedical health facilities for HIV testing when they are visibly sick and weak as they showed reluctance while they look healthy (Layer et al. 2014). One of the reasons for such a delay, Layer et al. (2014) asserted, were either due to the internalised stigma such individuals may receive from their domicile and religious communities, but also because they may be engaged in the use of health approaches other than biomedicine. Even when within the biomedical health systems, PLHIV often seek care from different facilities without disposing themselves towards HIV testing or treatment. As stated by Layer et al. (2014, 3), “medical care was sought at multiple health facilities for recurring illnesses” that may be HIV related “but HIV testing and counselling (HTC) was rarely recommended during these visits”. There was also a laxity by faith healers in the study to recommend their HIV patients to biomedical health facilities to receive health services. The low eagerness to recommend people who might be HIV positive to undergo testing by some faith healers, said Neddermeyer (2006), is because most of such healers believe that “everything in the universe is Spirit, each thing in it is of the same Spirit and it is all connected”; hence, all treatments are to follow the spiritual route.

South Africa is one of the African countries which has a high record of both HIV prevalence and the published studies around the practice of medical pluralism. As earlier stated, the burden of HIV in South Africa increased from the early 1990s, peaking in the mid-2000s. This was visible from the less than 1% of the South African population known to be living with HIV in the early 1990s to around 29% as in 2003 (Hunter 2003, 689). This was estimated by the WHO in 2004 (WHO, UNODC and UNAIDS 2004) at 1 600 daily new HIV infections. While the HIV/AIDS burden was increasing, there was also a momentum built by the South African

government in tackling the pandemic. Johnson (2004, 107) stated the primary reason for this build in momentum against HIV/AIDS as follows: for a growing number of African states, AIDS can no longer be understood or responded to as primarily a public-health issue: it is a political issue, a development issue, and a security issue, one that requires a comprehensive strategy to mobilise social and political resources. He went further to state that South Africa was seen to be in a good position to lead a “high-profile and comprehensive response to AIDS” as it had built “a strong and diverse network” before 1994 “to link governmental organizations, researchers, and health workers concerned with AIDS with antiapartheid political groupings” (Johnson 2004, 107-108). This ground work contributed to the “largely democratic and highly consultative” processes between government and civil society in the development of health policies in the country (Johnson 2004, 108). Such interactions, said Schneider and Stein (2001, 723), created the impression that “enlightened forces in civil society would work together with the new government to steer the rapid implementation of a well-formulated and rights-oriented National AIDS Plan”. Such, was the case for some time until the early 2000s, which is the so called “denialism”<sup>11</sup> period where the South African government was seen as being slow to responding to the HIV spread and the need for urgent rollout of treatment (see, for example, Butler 2005; Mbali 2004; Nattrass 2007; Schneider and Stein 2001).

However, although there was a general reduction in new HIV infections in the late 2000s, the cumulative number of infected persons had risen from 4.72 million in 2002 (Statistics South Africa 2002) to 7.03 million in 2016 (Statistics South Africa 2016, 6). Due to this HIV burden in the country, the development of governmental policies and programmes leaned towards tackling HIV/AIDS treatment and related issues, such as factors leading to infection, were initiated and gained traction (see, for example, Iwuji et al. 2013; Naledi et al. 2011; Orne-Gliemann et al. 2016; Tanser et al. 2013). In support of this agenda, there has been massive rollout and provision of ART in many South African communities. According to Naledi et al. (2011, 19), “the introduction of the antiretroviral programme in 2003 provided renewed hope [to PLHIV], the promise of increased life expectancy, and reduction in the burden on health services”. They also stated that this introduction “provided a welcome morale booster for health workers, who reported taking strain from both their working conditions and the increasing numbers of patients dying from HIV-related causes without availability of an

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<sup>11</sup> This was a period in South Africa where the then President of the country, Thabo Mbeki, was seen to be against the rollout of ART due to a denial of HIV being a leading factor contributing to AIDS (see Butler 2005; Mbali 2004; Nattrass 2007; Nattrass 2008; Schneider and Stein 2001; Schneider and Fassin 2002).

effective biomedical intervention” (Naledi et al. 2011, 19). In 2016, the South African government, in line with the directives of the WHO, began offering ART to everyone who was living with HIV or tested positive to HIV, regardless of CD4 count (Orne-Gliemann et al. 2016; WHO 2015). This step was taken in line with the UNAIDS’s call for immediate initiation of anyone with HIV onto ART regardless of CD4 count as a way of achieving 90% known status of PLHIV, 90% enrolment on ART and 90% viral load suppression as at the year 2020 (Iwuji et al. 2013; Tanser et al. 2013; UNAIDS 2014). The intensive introduction of ART, however, has not yielded the hoped outcome for HIV/AIDS treatment as studies have shown that there is either a delay of people undertaking testing to know their HIV status, a delay in getting into the treatment regimen, or a dropout from treatment (see Colvin et al. 2014; Govindasamy et al. 2012; Rosen and Fox 2011; Moshabela et al. 2011; Mugglin et al. 2012; Pantelic et al. 2015).

Peltzer et al. (2008, 2) noted that “anecdotal evidence from South Africa suggested that a number of ART patients resort to traditional medicine after experiencing side effects from ART” without necessarily consulting their ART providers before such use or informing them of such use. Such use is present despite the caution raised against it by the South African National ART Treatment Guidelines (Department of Health 2004), which places an expectation on PLHIV to disclose their use of any non-clinically prescribed or given medication when in any biomedical health facility as a way of avoiding contraindications and adverse drugs effects. This act of non-disclosure may not be peculiar to South Africa alone as a study conducted in the United States (Dwyer et al. 1995, 18) also showed that up to 70% of such patients do not disclose their use of other non-biomedical treatments to their doctors.

Although multiple factors have been identified as role players in the spread and management of HIV/AIDS, the origins, nature and treatment of HIV/AIDS has been conducted and provided through biomedicine. This precedence leads to the expectation on PLHIV to maintain a highly restricted and controlled ART treatment within the biomedical health provision system as it is within this treatment regimen that they will gain improved health status (Peltzer et al. 2008; WHO 2017). A deviation from this regimen is believed to cause delay in seeking treatment or resistance to the prescribed ARVs. Peltzer et al. (2008, 2), however, noted that amongst patients who deviate from the formerly prescribed treatment standards, “few data are available on the prevalence and patterns of traditional and alternative therapy use”. Thus, some studies show that there continues to be a lower than expected number of people seeking HIV care and treatment or dropping out of the mainstream medical system (see Colvin et al. 2014;

Govindasamy et al. 2012; Rosen and Fox 2011; Mugglin et al. 2012; Pantelic et al. 2015). Pantelic et al. (2015, 41) for instance, in their study of HIV positive parents in a rural South African community asserted that “medical pluralism emerged as a persistent negative predictor of ART utilisation among those needing it”. This conclusion was reached based on their observation that 30.2% of the study participants practised medical pluralism and were not on ART while 20% practised medical pluralism while on ART. Their reason for such a difference was that the delay in HIV testing or dropout was due to conflicting medical services. However, Pantelic et al. (2015, 42) noted that the quantitative evidence shown in their study as well as the findings of other studies (such as Horwitz et al. 2013; Moshabela et al. 2011; Muhamadi et al. 2011; Unge et al. 2011) that looked at the role of medical pluralism on HIV testing, ART uptake, and dropout of care, were limited, thus requiring continuous research in the area in order for more “firm inferences” to be made on the role of medical pluralism in the health care seeking of PLHIV.

In 2012, for instance, Ferguson et al. stated that prevention of mother-to-child transmission (PMTCT) programmes in Sub-Saharan Africa found that 38-88% of known HIV positive and ART-eligible women identified in PMTCT services fail to initiate ART. A meta-analysis by Mugglin et al. (2010) of a study tracking patients from HIV testing to ART initiation indicated that 72% of patients had a CD4 count conducted, among whom 56% were eligible for ART, and of these, only 63% started ART (Mugglin et al. 2012, 1510). The use of plural health care was highlighted in the study as a major cause of the delay or complications experienced in treating PLHIV. Such and other similar propositions; however, have been made without an exploration of the experiences of PHLIV in using these systems while on HIV care. This claim, however, was rebuffed by Appelbaum et al. (2015, 77) who asserted that “all participant groups (in their study) expressed different motivations for traditional African medicine use among patients receiving ART, many unrelated to treating HIV ... such as success in business, sexual virility, ridding oneself of poverty”. The study, however, does not provide much information on the experiences of the patients in navigating these systems and the possible effects of using these systems on their health and their HIV health-seeking journey. Considering some of the limitations in the mentioned studies, this study also gives room for the exploration of the experiences of PLHIV who may not be on ART but may be active users of biomedical facilities. Including individuals who are not active ART users allows us to also gain knowledge of their experience and how their use of plural health played a role in their non-use of ART.



## **1.6 Need for this Study**

Some critical questions that will continue to be asked in the discourse of medical pluralism are as follows: is medical pluralism responsible for delayed HIV testing, uptake of ART and drop out of care? If yes, partly or solely, to what degree, a major factor or a minor factor? What are the other factors, if any, contributing to the delay in HIV testing, uptake of ART and drop out of care? While many studies flag medical pluralism and its users as major contributing factor in the delay of HIV testing, uptake of ART and drop out of care, the role played by other factors in the dent on HIV care, such as the belief systems of the users, those of the health providers and how these affect the health-seekers' uptake or maintaining of care are often ignored. This focus on medical pluralism and its users, however, does not often bring clarity on when, why and how users of plural health care engage in plural health use. Therefore, a major question that needs exploration is regarding how users of medical pluralism have been able to maintain this usage and why they are able to maintain the practice of what seems, from an outside observation, a chaotic system. With a closer exploration of the experiences of the PLHIV using the plural system, a broader understanding of the practice of medical pluralism can be developed. This study explores the experiences of PLHIV in using plural health care, when and how they use and negotiate the different systems and how they are able to maintain consistency of being plural health users despite the disapproval of their biomedical health practitioners, from whom they receive their HIV treatment.

This was done by probing which health systems they use, what stage of their illness they use the different systems and services, their reasons for using the different systems, and how they navigate the different systems and services they receive. Not only does this study seek to comprehensively understand the patterns involved in the practice of medical pluralism, it also seeks to expand on how these patterns play out and the reasons for such patterns. The study takes the discussion around health care delivery from the long-standing duality between traditional health care and biomedicine to a context whereby focus is placed on the users and not only on the systems. It brings to fore why and how PLHIV are able to navigate between the complex interplay that exists between the health care provision systems despite the differences in their understanding and approach to health illness. Also, exploring the views of each of the systems' health providers on their role in curbing HIV/AIDS and the roles of other health systems, enables us to understand some of the barriers entrenched in each systems' view of itself and the other systems. This exploration shows us how such barriers contribute to creating division of loyalty to the different health systems and providers used by the PLHIV, which in

the end can endanger their healing process. This study will add to the developing pool of knowledge on medical pluralism and thus contribute towards building the evidence on the need to address the tensions within the existing medical systems and how such tensions affect users' health-seeking behaviours and health.

This study presents a better understanding of the health-seeking experiences of PLHIV in using a plural health system and their motivations towards this use. It also allows us some knowledge into the types of treatments they receive from the different providers; how they negotiate the treatment services they receive; and how this usage and negotiation influence their initiation, progression and retention in HIV care both positively and negatively. Having a better understanding of the experiences of seeking plural health care by PLHIV will allow for better intervention procedures and an appreciation and utilisation of the positive treatments that benefit PLHIV from the different health care providers. It will also enable us to focus more on finding the appropriate obstacles to early initiation to HIV care, ART, low cost of service provision and retention in care.

### **1.7 Research Problems and Objectives**

To explore the stated gaps in research and meet the objectives of this study, the following key and secondary questions are considered. The following were the key questions of the study:

1. Why do PLHIV seek plural health care despite the rejection of such health-seeking behaviour by biomedical practitioners?
2. What forms of health conditions do PLHIV present to the different health approaches they visit?
3. What forms of treatments do PLHIV receive from the different health approaches they visit?
4. How do PLHIV negotiate and use the various treatments and health services offered by the different health approaches?
5. How aware are PLHIV of the seemingly inherent tensions between their plural health service providers?
6. How does this tension influence their use of the health services they receive?

Medical pluralism is embedded in and influenced by the health approaches used and their providers, who sometimes have varying views towards health and illness and how these should be approached. This study also unpacks the perceptions and beliefs each system has of itself and of the other systems in terms of HIV/AIDS healthcare service provision. This enables us to understand some of the barriers entrenched in each system's view of itself and the other systems, the tensions between the systems and how such barriers contribute towards creating complexity in the health-seeking behaviour of PLHIV. Most studies (see King 2000; LaMeaux 2015; London et al. 2003; Louw and Pretorius 1995) have presented us with what each system regards as its role in the fight against HIV/AIDS. This study goes further in teasing out the systems and their practitioners' understandings of the roles of other health systems. These views contribute in shaping the choices and use of plural health care systems by people PLHIV.

Thus, the questions answered within the broader context of this study were:

1. What do the different health systems used by PLHIV understand as their role and the role of other health systems in combating HIV/AIDS?
2. What are the existing differences in health approaches and tensions between the major health systems and how do these affect the health-seeking behaviours of PLHIV?

## **1.8 Structure of the Dissertation**

This dissertation is structured into six chapters, each containing a major theme of discourse but also closely interconnected. The introduction chapter serves as the background to all the discussion in the thesis, the methodology chapter serves as a guide to how the study was conducted, while Chapters Three to Five show the findings of the study. Each of these findings chapters serves as a precursor to the chapter that follows it. The conclusion chapter weaves a thread through all the chapters, explaining the patterns and mechanisms used by the study participants in using plural health care.

### **CHAPTER ONE: Background and Literature Review**

This chapter firstly looked at the different understandings and the use of the concept of medical pluralism, based on views of health systems, illnesses or geographical regions. The chapter highlighted the contested understandings of medical pluralism, understandings which are fundamental in how the effects of medical pluralism are viewed in the health-seeking behaviours of PLHIV. Although medical pluralism is often seen as a negative factor in health-

seeking, the chapter brought to the fore some of patterns in which medical pluralism has been recorded in literature, patterns which leave gaps in the understanding of the practice of medical pluralism, hence yielding partial findings and conclusions. Literature, as shown in the chapter, shows how the practice of medical pluralism is complex and often marred with tensions, especially between the different health approaches used by plural health users, but also within the users in knowing when to use what system. The chapter also highlighted the three major health approaches used by plural health users within the study community and how the three approaches are understood in literature.

## **CHAPTER TWO: Research Methods, Methodologies and Theoretical Frameworks**

A clear understanding of the map of a journey sheds light and makes the journey easier than when a map is not available. The methodology chapter of this thesis serves as the map of the study, describing all the processes followed in the development, implementation and analysis of this thesis. This chapter deals with the methods, methodologies and theoretical frameworks used in the course of the study. The study used an ethnographic and qualitative approach with recruitment of participants through theoretical sampling (which is an aspect of a grounded approach), with data collected through repeat interviews. Collected data was analysed through thematic formation whereby the concepts discovered in the data were analysed towards understanding the notion of medical pluralism as experienced and practised by the study participants. The chapter shows the techniques and manners in which the chosen methods were used and the reasons for their use. It takes a step-by-step approach to explaining how participants were recruited and how the data was collected and analysed. In exploring the methods and methodologies used in this study, room was created for clarifying the reasons for using each method and its possible impact on the study outcome. Doing this allows for a clear reading and understanding of the findings of the study in light of the methods used.

## **CHAPTER THREE: Use of Multiple Health Approaches by People Living with HIV: Intentions and Reasons**

The chapter looks at what health approaches the participants used for the different health conditions they had suffered in their lives. This was to enable the reader to take note of the different approaches involved in the plural health-use of the participants. Considering that biomedicine remains the primary source of treatment for PLHIV for their HIV treatment, the use of biomedicine was prevalent during the study, for the treatment of HIV and for other health conditions. Hence, this chapter explores the experiences of the PLHIV in this study and how they make use of the biomedical health facilities in the community. The chapter looks at how

the participants made use of the clinics, hospitals, private doctors and chemists to treat illnesses such as diabetes, tuberculosis, asthma, epilepsy, body pains and HIV/AIDS. This usage was consistent with their views and understandings of those illnesses and how they should be treated, hence, why they opted to make use of biomedical health facilities.

The chapter also dealt with the traditional and religious healing approaches utilised by the participants. The chapter showed how these systems were also often utilised concurrently, sequentially or in parallel. The chapter showed that while a participant may suffer from a particular health condition, seeking healing for that health condition may involve visits to different health providers, concurrently, sequentially or in parallel. This chapter further presents the motivations and treatment mechanisms used by the PLHIV in this study.

#### **CHAPTER FOUR: Perceptions of and Experiences of Complexities, Dilemmas and Tensions in Plural Health Use**

While the previous chapter presents the health systems utilised by the study participants in seeking health, it was evident that this health journey was not a smooth-sailing venture. Often, the participants' choices of health system were met by resistance from different sources, particularly health providers, but also by some family members. This chapter discussed the concepts of 'tensions' and 'complexities' as experienced and shared by research participants as opposed to how tensions and complexities are generally understood in literature of medical pluralism. These tensions are the lived experiences of the participants in deciding what health system to use, for what illness and at what stage of the illness. The tensions and complexities are also derived from the pressure or segregation received by participants from the health systems and providers they use, some of whom often discourage them from using certain health systems. Thus, in some instances, some of the health providers expressed some level of 'understanding' for the patients, thus allowing them to make use of health approaches that they both deemed fit for the patient. Such gatekeeping, however, goes on to show the structured violence positioned in the health-seeking route of the participants. The chapter also presents the understandings of the different health care providers as to what the different health care systems used in the community can contribute towards the fight against HIV/AIDS.

#### **CHAPTER FIVE: Support Systems and Mechanisms used in Navigating and Creating 'Harmony' or Resolving Tensions in Plural Health Use**

The chapter captures the mechanisms used by the primary participants in different systems, thus marrying the rather complex systems and becoming the unifying factor between the

different approaches. It shows us some of the ‘minor’, but critical, practices used by the participants to allow them to successfully navigate the plural health system while still remaining and progressing on their cascade of care. The chapter presents strategies such as the discontinuation of using some herbs that are considered ‘strong’, the discontinuation of any rite that involves spewing, separation of time between taking one’s ARVs and the use of herbs, as some of the mechanisms used by the PLHIV in the study to navigate the tensions they experience in using plural health systems. It also presents us with the experiences of participants who dropped out of ART or did not start ART due to their plural health-use. Thus, the chapter compares these categories of participants and how they understand their use of plural health and how this, in turn, affects their health-seeking behaviours.

## **CHAPER SIX: Conclusions and Recommendations**

This chapter contains the conclusion of the thesis by providing a summary of all the study findings. This development arose from the data showing how medical pluralism is practised amongst PLHIV. The various aspects of medical pluralism and their basics as noted from the lives of the PLHV in the study were also considered. Such aspects related to the factors and circumstances that either promote or hinder the use of plural health amongst the primary participants. They included the personal and external circumstances faced by the PLHIV when making decisions on using plural health. The personal factors or circumstances included their health knowledge, their cultural and religious beliefs, their previous health-seeking experiences, as well as their socio-economic situations. The external factors, which were often beyond the control of the PHIV, were the tensions between the different health approaches they use, the belief systems of providers, both health and religious, as well as community beliefs and values. The chapter also presents recommendations for implementation and further studies based on the findings from this study. Some of the recommendations include capacity building within health approaches, knowledge sharing within and between health approaches, collaborative work between health approaches and the education of health users.

### **1.9 Conclusion**

In most of the reviewed literature, a persistent reality in different societies and systems is the existence of the great complexities faced by PLHIV in seeking plural health care. These complexities are mainly due to the differences within the different systems they use, but also due to the lack of understanding or general agreement in understanding medical pluralism. The concept of medical pluralism from different contexts where people are said to be practitioners

or users of plural health systems was firstly teased out in this chapter before delving into the practice amongst PLHIV. While in some contexts, the practice is regarded as complementary or as an alternative treatment (de Andrade and da Costa 2010; Hughes 2014; Lee and Orman 2012; Matthews et al. 2005), in other contexts, it is regarded as integrative medicine or health (see Adler 2002; Grace and Higgs 2010; Hughes and Mbamalu 2015). Despite these differences in understanding, the concept continues to be used widely across contexts.

The difference between the different systems used in medical pluralism and how medical pluralism is perceived thus creates tensions not only between the systems, but for the users of the systems as they find it difficult to know when to use the different systems without being seen as “bad patients” (Ondenge et al. 2017). Due to the existing tension between the different approaches, PLHIV may be forced to receive partial or ‘*harmful*’ ‘*treatments*’ and services from health care providers as providers strive to retain their customers despite their inability to adequately assist the patients, an act which may in the end affect the patients’ health directly or indirectly. Another possible reason behind these existing pluralistic tensions is that patients end up concealing their use of other forms of health care services from their providers, especially physicians, even when such treatments may not be harmful (see Peltzer et al. 2008, 255). Hence, even when patients make use of harmful alternative medications, the appropriate physicians are unable to render necessary or timely assistance. One may argue, thus, that understanding the circumstances in which PLHIV make use of plural health care systems and services is highly relevant towards creating more open and safe channels for health care seeking. This chapter has focused on teasing out the practice of medical pluralism by PLHIV in different societies and the health systems used as recorded in literature. Doing this has enabled me to not only take note of the gaps in the literature, future needed areas of study, but also to consider how to go about creating a better understanding of this practice to build on existing knowledge in the discourse.

## CHAPTER TWO

### Research Methods, Methodologies and Theoretical Frameworks

#### 2.1 Introduction

Due to the curious nature of the human being and the need to solve problems around us, ways of understanding the world and the phenomena we experience daily have been sought through the ages. Bertram and Christiansen (2014) stated that there are three major ways or methods of making sense of the world: reliance on myth or folklore, reasoning (philosophy) and research (Bertram and Christiansen 2014, 7). Different phenomena and problems, however, require approaches that best suit them and allow for the most efficient and meaningful discovery of each phenomenon. This can be seen as a demystification process, whereby pertinent information about the phenomenon is gained. Hence, through research, this study, which sought to unpack and increase the understanding around the experience of PLHIV using plural health, required the gathering of pertinent information about the experiences of the participants. The pertinent scientific and systematic information on the experiences of the research participants was sought by drawing evidence from their daily experience of seeking or providing – in the case of providers – health. To gain access to this evidence, data, which is a set of information collected for the purpose of analysis (Kothari 2004), needed to be gathered. To gather a study-relevant set of data, however, there was a need for a research design. A research design, which is a methodological schema and systematic approach, helps to construct the map of a study (Durrheim and Wassenaar 2002). This designed and planned approach of observation, according to Durrheim and Wassenaar (2002), is what differentiates research from other forms of observations as research is systematically planned and strategically carried out and analysed.

While there are many styles of conducting systematic research such as case studies, life histories, action research, surveys, experimental research and correlational studies through qualitative, quantitative, or a mixed-method approach, the approach taken depends on the type of quest sought through the study. This study, being about the lived experiences of PLHIV and their use of a plural health system, required and made use of a qualitative ethnographic approach to data collection. Corbin and Strauss (1990, 10) defined qualitative research as a “type of research that produces findings not arrived at by statistical procedures or other means of quantifications”. In other words, it is an approach which does not seek the use of



mathematical processes to both data collection and or interpretation, but is mainly carried out through in-depth data collection and analysis in order to discover the concepts in the data and their relationships for the purpose of theoretical development or explanation (Corbin and Strauss 1990).

While research often takes a step-by-step progression through designing, sampling, recruitment, data collection, and analysis, this study, based on its data collection approach, was made up of back and forth movements between the different steps and stages in the research. In doing this, while the sections on sampling, data collection and data analysis have all been written out separately in this thesis, these processes occurred simultaneously during the data collection. Analysis of each interview, using open coding, led to the next step or direction to be taken. In some cases, this was a repeat interview or visit, and in others, the recruitment of a new participant who was identified based on theoretical/purposive sampling as a link to the visited person and who played a major role in the health-seeking behaviours of the participant.

This chapter looks at the methods, methodologies and theoretical frameworks used in this study. It also provides reasons for their usage and how they were used to achieve the required outcomes of the study. Research methods, as defined by Kothari (2004, 7-8), are the instruments and techniques used by researchers in conducting the operations of research; research methodologies, on the other hand, are ways of systematically solving a research problem by studying and understanding the various methods used in a study together with the reason for their usage.

## **2.2 Research Site**

This study was conducted at Hlabisa sub-district of the uMkhanyakude district in KwaZulu-Natal, South Africa. uMkhanyakude is a 13,855km<sup>2</sup> area in northern KwaZulu-Natal. Hlabisa sub-district covers parts of the Mtubatuba local authority and the Mpukunyoni tribal areas in the southern part of the uMkhanyakude District. uMkhanyakude District lies along the coast of the Indian Ocean. It shares local boundaries with Zululand and King Cetshwayo Districts and international borders with Mozambique and Swaziland. The district is the second largest in the province with five municipalities: Jozini, Big Five, Hlabisa, uMhlabuyanlingana and Mtubatua, and 68 wards (Local Government Handbook 2017).<sup>12</sup> uMkhanyakude has a population of about 638 011 people, 53.3% females and 46.7% males, the majority of who are

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<sup>12</sup> See Appendix 15 for map of uMkhanyakude.

amaZulu. Hence, isiZulu is the generally used language in communication in the district. The population density is 46 people per km<sup>2</sup>, thus making it the most sparsely populated district in KwaZulu-Natal province.<sup>13</sup> About 54% of its households are headed by the 53.3% females and 46% by the 46.7% males. About 51% of the population is below the age of 19. Amongst the population aged 20 and above, 17.8% have no formal education, 31.1% are matric holders while only 6.4% have higher education qualifications. The district is ranked as 51<sup>st</sup> of 52 most deprived districts in the country (District Department of Health – uMkhanyakude 2015, 14-15). The main economic activities in the district are agriculture, as it is a rural area with fertile soil, trade, especially of crafts, and tourism as it prides itself with the Isimangaliso Wetland Park (District Department of Health – uMkhanyakude 2015; Local Government Handbook 2017).

The district has five district hospitals, 56 primary health care (PHC) facilities – clinics – and 17 mobile teams. These facilities, however, are not evenly distributed round the district. Mtubatuba, for instance, despite having 28% (179 378) of the district population lacks higher level care. It has no hospital or a Community Health Centre. The cost of primary health care in the district has been estimated to be R108 per person – ranging from R82.5 in Hlabisa to R116.4 in uMhlabuyalingana. Both, however, are below the R210 national average of funds directed for PHC. The expenditure per capita for the district’s PHC is R388 and only 3.9% of the population in the district has access to medical schemes. This will mean that a whopping 96.1% of the population mainly depend on public health services if they are to undergo any check-up or treatment. There is limited access to the PHC facilities in the District due to the long distances in getting to clinics as some of the clinics are outside a 10km radius (recommended maximum spacing), the poor road infrastructure or cost of transportation. In most cases it is a combination of more than one of these factors. For instance, only 5% of the roads in the District are tarred while the other 95% are either sandy or gravel. These poor road networks, as stated in the District Department of Health – uMkhanyakude’s (2015, 13) district health plan, “contribute to regular breakdowns of motor vehicles that affect the transport fleet and leads to poor EMRS – emergency medical response services – response time”. The community rely heavily on public transport when accessing the available health facilities. As such, rainy seasons present more difficulty in using the roads which become muddy and slippery.

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<sup>13</sup> See Appendix 14 for map of KwaZulu-Natal.

Clinics that are highly accessible, however, are often overloaded with patients and are inadequately staffed. Visits to the clinics within the district are conducted by the doctors from the five hospitals in the district at least once a month with an average workload of 34.2 patients per visit (District Department of Health – uMkhanyakude 2015). This is because there are no full-time doctors in the clinics. The government-run clinics in the district offer free primary health care services, including HIV and AIDS care services. Patients requiring hospital care are referred to one of the five district hospitals that may be in close proximity to the referral clinic. Despite the district being one of the most socio-economically disadvantaged districts in the country, its link to Mozambique and Swaziland through its borders, mean its health facilities are utilised by foreign clients, often at unbudgeted costs (District Department of Health – uMkhanyakude 2015).

One of the major factor for choosing uMkhanyakude as the study site was because it has been shown that the uMkhanyakude District has the highest prevalence of HIV/AIDS in KwaZulu-Natal (35% in 2012 according to Cullinan 2014). According to the report of the District’s Department of Health:

HIV/AIDS remains the biggest challenge to the health care system in the District. HIV/AIDS adversely affects life expectancy, maternal mortality, perinatal mortality, child nutrition, child mortality, tuberculosis incidences and cure, and incidence of MDR-TB and XDR-TB, and impending progress towards Millennium Development Goals (MDG). (District Department of Health – uMkhanyakude 2015, 9)

Despite the current high rate of HIV prevalence in the district, it has made some progress in the management of HIV/AIDS over the past decade. It is reported that due to the HIV/AIDS programme in the District, about 58 643 PLHIV in the district are on ART; prevention of maternal to child transmission (PMTCT) is 1.7% leading to a drop in antenatal prevalence from 41% to 35.2% from 2007 - 2015; life expectancy has also increased by ten years (District Department of Health – uMkhanyakude 2015).

It has also been reported that black rural areas and places with a high HIV prevalence, such as uMkhanyakude, have higher chances of users of plural health care systems over urban, peri-urban and places with low HIV prevalence (see UNAIDS 2006). This was evident in a study

conducted by Pantelic et al. (2015, 42) where they stated that in line with most clinic-based studies within South Africa, their community-based study “suggest that respondents residing in rural areas were more likely to utilise multiple healthcare modalities than respondents from urban settlements”. This, they said, can be partially due to the lack of clinics or other primary health care facilities in rural areas as well as the quality of service received from the available few facilities. Thus, this site was chosen to conduct this study at as it is a rural area with a predominantly black population, most of whom form part of the 55.5% – 30.4 million – South Africans living below “the upper-bound poverty line (R992 per person per month (ppm) in 2015 prices)” (Statistics South Africa 2017: 14). The poverty level amongst the Black African population of South Africa has been shown to be the highest compared to Coloureds, Indians/Asians and Whites, as shown in the survey conducted by Statistics South Africa between 2006 and 2015 (Statistics South Africa 2017: 19).

While some of the communities and clinics in uMkhanyakude were visited during the course of the study, the operation of the study was conducted from the Africa Health Research Institute (AHRI), Somkhele Branch. During the conceptualisation of the study, 2015, the institute was known as the Africa Centre for Health and Population Studies, then Africa Centre for Population Health in 2016. The study was hosted at the institute as part of a Wellcome Trust-funded study at the institute entitled *The impact of medical pluralism on the cascade of care for people living with HIV/AIDS in rural South Africa* (Grant Number – 105825/Z/14/Z), which sought to understand the role played by medical pluralism on the progression of PLHIV on their cascade of care using both qualitative and quantitative methods over a period of four years, 04/2015-03/2019.<sup>14</sup>

### **2.3 Sampling and Recruitment Selection Techniques**

This study involved two major categories of participants, primary and secondary. The primary participants were PLHIV who were also users of plural health care. The secondary participants were health providers of PLHIV, in the study or not, who use plural health care. To identify and recruit the participants, multiple sampling and recruitment strategies were used. The foremost sampling approach was purposive sampling, which was based on the existence of

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<sup>14</sup> The Wellcome Trust is a UK based, but global charitable foundation which is politically and financially independent. It supports scientist and researchers globally to tackle major health issues, raise imaginations, spark debate and source for viable solutions to health issues (Wellcome Trust 2016).

PLHIV who were plural health users as well as the existence of health care providers of these health users.

Nine PLHIV were recruited as primary participants in study, irrespective of their stage of HIV treatment. Four of these nine primary participants were also traditional healers. Although the four primary participants were traditional healers, they were however, recruited primarily for being HIV positive. Although their expertise as traditional healers might have contributed to their views and attitudes towards medical pluralism, our focus in discussions with them was primarily as health users, although their expertise as traditional healers often became part of the discussions. Most (seven) of the participants were actively on ART while a few (two) were not on ART. The key criterion for their inclusion in the study was based on the theoretical view that there exist some PLHIV who make use of multiple health systems in seeking health, regardless of the reasons or purpose of such health-seeking. PLHIV who were on ART and those who were not on ART were included for a comparative view of the different ways in which plural health systems are used in the study community by PLHIV. Having nine primary participants for the study enabled the researcher to identify a low number of people with whom a deep qualitative observation could be carried out over a long period of time, 12 months, considering the context of the study time frame, while at the same time reaching saturation of the issues that arose in the study. All primary participants were above the age of 18, with the youngest being 28 and the oldest 61 years old. The choice of this age group was because the prevalence of HIV/AIDS has been shown to be highest in persons of this age group, especially 15-49 year-olds with a prevalence of 15.8% (Statistics South Africa 2016, 7). However, the presence of people of different and older generations was also critical to the study as the experience of people within the plural health system varies from one generation to another. The experiences of a younger generation might not necessarily be the same experiences encountered by older PLHIV. Although gender was not a primary recruitment criteria, due diligence was given to the need for some representation of both males and females in the study. This was considered because there could be differences in factors contributing to the use of plural health system and the manner in which it is used by those of different genders. Therefore, the researcher ensured representation of both males and females in the study community.

To recruit the primary participants, both purposive and theoretical sampling was used. According to Tongco (2007, 147), purposive sampling, which is also known as judgment sampling, is “the deliberate choice of an informant due to the qualities the informant

possesses”. This sampling technique is non-random; rather, the researcher decides, based on his or her set aim of what he or she wants to know through the study, and reaches out to people who are able and willing to assist in providing vital information to the researcher based on their knowledge and experience of the studied phenomenon (Bernard 2011; Lewis and Sheppard 2006). This choice is based on the belief that the researcher knows a particular group of people that are directly relevant to the research and would be of value to the study.

The primary participants were specifically targeted and there were three phases of sampling. The first phase was carried out through identifying users of plural health care from a study conducted at AHRI entitled: *The Health Care Bottlenecks Study* (protocol number – BE338/15), to be referred to henceforth as the Bottlenecks Study, which I was actively involved in from July 2015 to May 2016.<sup>15</sup> A section of the study population was made up of users of plural health. Permission was sought and granted by the Principal Investigator of the study for such participants to be noted and afterwards approached for possible recruitment and participant in the current study (see Appendix 2.1 for Letter of Collaboration from *The Bottlenecks’ Principal Investigator*). This purposive approach was conducted at the end of all Bottlenecks Study visits. This was so done to avoid having the same participants in multiple studies concurrently.

Initial identification was carried out by reviewing the Bottlenecks Study’s field notes and case summaries to identify participants that had reported being users of plural health care. Five potential participants were identified. From the five initially identified potential participants, a screening was conducted whereby participants with the closest attributes to the categories sought for the current study were selected. This selection was based on the theoretical assertion that there are PLHIV who make use of more than one health system at the same time, as such showing an ability to harness multiple health systems. After this screening stage, two individuals were identified as suitable to be interviewed first. Their suitability to participate in the study was based on the simple attribute of being open users of plural healthcare while on ART. This was as different to others who had been initially identified as potential participants.

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<sup>15</sup> The study was initiated by the network for Analysing Longitudinal Population-based data on HIV in Africa (ALPHA) in order to understand and deal with the problems faced during the process of providing HIV services, which in turn retard or terminate the progression of PLHIV on the continuum of care. The study was simultaneously conducted in host communities of seven health research sites based in six sub-Saharan countries, Karonga (Malawi), Kisesa (Tanzania), Kisumu (Kenya), Manicaland (Zimbabwe), Masaka and Rakai (Uganda), and uMkhanyakude (South Africa). I was a team member of the study and the field coordinator of the South African site. Through this involvement, I was able to traverse the research field, both the community and biomedical health facilities and gained a good understanding of the people and the lifestyle, health, social, cultural and spiritual, lived by the community members.

One such individual was excluded as he was considered unsuitable for immediate participation in the study as there were inconsistencies in his version of health-seeking behaviours with that of the clinic's database. While the clinic database recorded him as an irregular patient – a patient who does not fully comply with the advised clinic visits and collection of medication, the potential participant asserted that he was a dedicated ART patient. Therefore, even though he claimed to be using traditional medicine, it would have been difficult to trust his claims.

The other two potential participants were excluded from those to be immediately recruited due to the complex nature of their qualities. They were users of plural health services while also working as traditional health providers. Due to this, there would have been difficulties in ascertaining if their assertions were made as providers or users. This category of plural health users, however, was to be involved later in the study.

Two potential participants were only approached about five months after their participation in the Bottlenecks Study to ease any possible research fatigue. Due to my lack of fluency in isiZulu, I conducted the visits with the same fieldworkers who had interviewed the participants in the Bottlenecks Study. This visit was held both as a final visit for the Bottlenecks Study but with the intention of possible recruitment for the current study. The fieldworkers, who were residents of the District and amaZulu, were trained and experienced qualitative interviewers. The potential participants were informed of the current study, told why they were found to be suitable to take part and asked if they wanted to participate in the study, but were under no obligation. When a potential participant was unsure about his/her willingness to participate in the current study, he/she was presented with the information sheet of the current study and asked if he/she was willing to be visited again so that he/she could inform the fieldworkers of his/her decision. Using purposive sampling in this first stage of recruitment gave room for both direct identification and recruitment of this hard-to-find population from already known PLHIV who were also users of plural health care. This approach reduced any levels of stigma by removing any third parties from the process.

The second phase of recruiting primary participants for the study was conducted through a form of purposive sampling known as theoretical sampling. Theoretical sampling is an aspect of grounded approach, which is “theory-driven rather than data-driven” approach to sampling whereby interpretive theories are built from emerging data, tested and elaborated with new samples in the same study (Kielmann, Cataldo and Seelay 2012). The identified theoretical

threads/concepts influence the selection of subsequent participants. This form of sampling allows for a deeper concentration in the emerging themes and concepts in the process of data collection, which also involves analysis, as opposed to the piling of imperforated data. Some of the already recruited participants from the first phase of recruitment had partners or family members who were living with HIV and used multiple health systems, or played some role in the plural health-seeking of the already identified primary participants. Therefore, in order to develop an understanding of the identified concepts in the practice of medical pluralism of the participants using this approach, after each interview, the collected data was coded, analysed and the study hypothesis tested before further sampling and data collection. The research team was informed about such individuals, some of whom had been initially introduced to the research team as family members of the participants. For example, the discovery of the huge role played by the faith healer of a participant made the faith healer a likely participant in the study for the development of the thread arising from the primary participant. Such individuals were then approached by the research team, with the help of their already recruited family member, and in some cases, this process was initiated by the participants, to ascertain the keenness and willingness of such family members to take part in the study. With their consent, they were recruited into the study. They were fully informed of the study and their roles which involved at least three interviews or more if they were willing and available, and other visits that did not involve formal interviews.

Using this sampling approach aided the research team in reaching some members of the hidden population through individuals who were familiar to them. The presence of a familiar person helped to reduce the reluctance in openness often experienced in initial visits to research participants. In the case of this study, participants generally warmly welcomed the research team with whom they were familiar, even before their recruitment to the study. Using this kind of theoretical sampling as the basis for sampling participants for the study was to ensure that data was only collected from the personal experience of medical pluralism by the respondents, either as users or providers. This was to ensure that the data was of high quality and value due to the nature of the study, which required personal experience as opposed to opinions of non-affected individuals.

This process can, however, according to Bertram and Christiansen (2014) lead to biased sampling. Bertram and Christiansen (2014, 62) stated: “bias means that a person has an inclination for or against something or somebody. That means they cannot make an impartial judgement”. This could have been the case in this study, as in any other, due to the role of the



researcher's positionality. The researcher's positionality in this study was mainly in relation to the health approaches in the study. Being an African who believes in the role of ATM and a religious person having studied towards being a Catholic missionary, may have led to bias in how the researcher approached the different health approaches in the study and their users. To limit the possible bias that purposive sampling method may create and ensure that the study sample was representative of PLHIV who were users of plural health care without selectively choosing any pattern of care over another, constant comparison was used between the identified concepts. According to Corbin and Strauss (1990, 421), constant comparison "means that as an incident is noted, it is compared against other incidents for similarities and differences"; also "making comparisons assist the researcher to guard against bias" as the researcher's thoughts and beliefs are constantly challenged against the data. Using this procedure, the study team was able to identify, without bias, individuals that were linked to the primary participants based on how they influence their health choices. The procedure was then continued until no further identification of new concepts was made, a state also known as the state of saturation (Goodman 1961, 148).

The third phase of recruiting primary participants, which was also intended as an alternative recruitment strategy if saturation was not reached in the first two phase of recruitment, was a combination of both purposive sampling and theoretical sampling done through the health providers, particularly biomedical health practitioners. This choice was made due to the practicality of identifying patients who were HIV positive by this set of health providers as opposed to traditional healers or faith healers who might not necessarily have such information at their disposal. In this phase of recruiting primary participants, the assistance of health care providers was sought to identify and notify, from their patients, those living with HIV/AIDS who openly consented to making use of multiple health approaches. They were to identify and seek the consent of their patients living with HIV/AIDS to be contacted by the study team for a one-to-one recruitment visit. Visits were made by the research team to six of the clinics in the District where permission had been granted by the ethics committee and the facilities' stakeholders, the supervising hospital manager and the Department of Health, District and Provincial. Fridays, in most of the clinics, from the observations made before the data collection period, were the least busy days. Hence, these visits were mostly conducted on Friday afternoons, and when conducted on a different day, they were at lunch time or in the late afternoon when most of the clinics were less busy. This was because sensitivity was needed regarding the workload of the facility managers and staff. On our first visit to each clinic, a

request was made to meet the facility's Operational Managers (OM) at a time suitable to him/her. In most of the clinics visited, the OMs attended to us, either immediately when on break or after consulting the patients that were waiting.

In our meetings with the OMs or their representatives, we introduced ourselves and the study, presenting them copies of the study protocol and all the gatekeeper letters of the study, including the ethics approval. We were then taken to either the ART nurse or the HIV counsellor<sup>16</sup> for more direct assistance. Firstly, this was for familiarity as they were possible potential participants for the study. Secondly, this was for assistance in identifying and recruiting patients who admitted to being plural health users and were willing to be contacted by us. Thus, the study was also introduced to the ART clinics' staff members so they could explain it to their patients when introducing the study. The health care providers presented identified plural health users with the information sheet of the study and requested their permission to be contacted by us for possible recruitment. No contact was made with any patient until they voluntarily agree to the health provider to share their contact details with us. This was to avoid breaking the protocol of confidentiality prescribed for PLHIV, by protecting the identities of the PLHIV in the facility from the study team, until they choose to be contacted directly.

When a patient from the facility agreed to be contacted by the study team, their contact was then presented to the study team. To facilitate this process, the providers were given writing materials for writing patient details and stickers for identifying the files of such patients. The study team then took down the details from the providers in order to contact the patients for possible recruitment. The patients were contacted telephonically to set up a meeting on days most suitable to them in their homes. When contacted by the study team, the potential participants were also given an option to be part of the study or not, a decision which was not known to any of the nurses or counsellors who assisted in the identification and recruitment of the participants. This non-disclosure of the identity of participants who agreed or disagreed to be part of the study was to protect the identity of the recruited participants from the health care providers. Hence, they were not made aware of those patients who agreed to be part of the

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<sup>16</sup> The HIV counsellors in this study were "facility-based" lay health workers. According to the WHO (2013, 1), a lay health worker (LHW) is a "health worker who performs functions related to health care delivery and is trained in some way in the context of an intervention, but who has not received a formal professional or paraprofessional certificate or tertiary education degree". It also states that other terms used in reference to LHWs in different parts of the world included "community health workers' (CHWs) and 'village health workers' (VHWs)." (:1). The level of education and job description of LHWs vary from one setting to another. This is often based on the health priorities of each community (United Nations Children's Fund 2004; Zeelie 2014).

study. Although no potential participant openly objected to be part of the study, continuous postponement of visits by some potential participants, even before knowing what the study was about, was taken as a lack of interest to participate in the study. Although there was a conscious effort by the study team to promote the protection of the confidentiality protocol protection PLHIV, there was a possibility of bias in recruitment by the health providers, which was beyond the control of the study team. This possibility could be that the health providers identified and recruited individuals they whom share a particular line of thinking in relation to the practice of medical pluralism. Such a possibility can be seen from the high representation of traditional healers in participants recruited from the clinics. This high representation could also be due the openness of traditional healers to share their experiences of practising medical pluralism as opposed to individuals whose health views and practice cannot be easily identified. Hence, it is acknowledged that the high representation of traditional healers in the study could have created bias in views, but also a limitation in capturing more diverse views on the practice of medical pluralism. The openness and fair representation of the views of study participants that were not in line with those of the traditional healers aided in mitigating the high effect possible biases.

This recruitment processes were maintained until full saturation or an attainment of the least intended number of primary participants (nine) for the study was met. This multiple sampling approach was critical to reaching the hard-to-find population of PLHIV who were on ART and use plural health care. Although health providers readily had knowledge of PLHIV who were on ART, the key factor was the openness of the plural health users to the biomedical health providers. Most of the participants recruited through this process, however, were users who were also traditional healers. The reason for such an occurrence can be linked to the fact that PLHIV who are users of plural health still find the biomedical health system highly stigmatising. Traditional health practitioners, however, in this case, appeared to be more at home with their plural healthcare-use and openly discussed it with their biomedical health providers on their visits to the ART clinics. Besides, being visibly seen at the ART clinics wearing items only used by traditional healers gives away their identity as traditional healers.

Using a standard sampling method which required the availability of a list of a population from which participants could be easily selected was impossible for this study. This was because the primary study population, PLHIV who make use of plural health care, is a hard-to-reach population. Firstly, due to the continued stigma faced by PLHIV in their communities despite the wide knowledge of the illness, but also due to the double stigma faced by PLHIV who are

users of plural healthcare, especially from biomedical health practitioners. Thus, it was important that the sampling methods used in identifying and recruiting the primary participants in this study were appropriate.

The secondary group of participants were the health care service providers from the three major health care approaches focused on in this study: traditional, biomedical and faith healing. There were three traditional healers (excluding the four who were also primary participants), five biomedical practitioners (two HIV counsellors and three ART nurses)<sup>17</sup> and one faith healer. The ages of the health providers ranged from 41 to 84 years. Their years of experience (that they had dealt with and understood the dynamics of medical pluralism as experienced by their patients) ranged from 10 to 50 years. One of the criteria for recruiting a provider, whether they were ART nurses, counsellors, traditional healers or faith healers, was that they must have attended to patients whom they knew were users of plural health. Such providers would have better understanding of how their practice requires them to handle such patients and practical experience of working with them.

In recruiting secondary participants for the study, both purposive and snowball sampling were used. Snowball sampling has been defined by one of the founding fathers of the method as “a random sample of individuals drawn from a given finite population” (Goodman 1961, 148). Each individual from this randomly chosen sample is then requested to identify different individuals from their circle. The next group of identified individuals are also expected to do the same, identify individuals from their circle, but not those already identified in previous selection stages. The initial providers recruited were the providers of the primary participants in the study. The participants informed us of the providers and we asked if they could link us to them. In our presence, the participant made calls to the providers and took us to visit them in person. In situations where they did not have the contact details of the providers, especially their biomedical health providers, they told us the name or names of the practitioners who often attended to them. We afterwards visited the facilities, introduced ourselves and the study and attempted to get a sense of the practitioners’ knowledge of the participants and their health-seeking behaviours. Some of these participants were well-known by their providers, due to their “uniqueness”, which was often regarded as “stubbornness”. This approach was relevant as it helped us not only reach “random” health providers, but providers who were directly

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<sup>17</sup> The counsellors were biomedically trained personnel, based at the health facilities, and conduct services such as HIV testing and counselling.

linked to the primary participants of the study. Recruiting the primary participants' direct health care providers strengthened not only the narratives and health-seeking history of the participants, but also our understanding of the links and complexities in dealing with medical pluralism from different perspectives; especially the perspective of practitioners whose patients openly make use of plural health care.

The second approach of recruiting the health care providers was through purposive sampling. In this approach, we visited the hospital and clinics which were part of the study, introduced the study to the Operational Managers, who in turn introduced us to the ART nurses and/or counsellors. The ART nurses and/or counsellors were introduced to the study by the research team who responded to any questions the providers had for clarification. When satisfied and willing to take part in the study, the providers were provided with the consent forms. This approach was also used in recruiting more faith healers, whose churches the researcher attended in order to observe the proceedings and informally discuss church events with members. In the case of the faith healers, the research participant sought meetings with the healers at times they found suitable. These meetings involved introductions of the study team and the study to the healers. If they agreed to participate in the study, the healers were given consent forms for signing. Purposefully recruiting health providers from their facilities and churches allowed, while it provided no guarantee of identifying providers who might have dealt with plural health users, gave us the opportunity to recruit the providers who consented rather than being recommended by their patients who would have been primary participants in the study. This diversified the recruitment process and allowed the providers to feel more independent in their decision and choice of taking part in the study, not by a default process of being a provider to a study participant. On meeting with all providers, especially when purposefully sampled from health facilities, they were asked if they had attended to PLHIV who were users of plural health. Responding in the affirmative was vital as we needed to ensure that we only recruited practitioners who had experience of dealing with patients who are plural health users.

The third phase of recruiting the health care providers was through snowball sampling, which was mainly carried out with traditional health practitioners. In this approach, the head of traditional healers identified and recommended some of the healers in the local community who might have had visits from PLHIV, even if such visits were for reasons other than HIV treatment. Nonetheless, in meeting such healers, the study team introduced itself to the healer, seeking to know if the healer had any contacts or treatment of PLHIV who were also users of other health systems, especially if they still kept their appointments at the clinics for their ART.

As traditional healers do not practice open sessions as in religious houses where recruitment was done purposively or biomedical health facilities where there was a structure and hierarchy, recruiting traditional healers was most viable through snowball sampling.

The method allowed us the opportunity to identify healers who were aware of the practice of medical pluralism and had treated patients who make use of plural health care in seeking health.

On our first visit to participants, an introduction of the study team was made, particularly for those who were not familiar with us if they had not been recruited from the Bottlenecks Study. Participants were handed copies of the study information sheet and informed about the study, including those recruited from the Bottlenecks Study. Their roles in the study were fully explained and they were given space to ask any questions for clarification. When fully satisfied, participants were provided with copies of the study consent forms for signing. A set of the forms were then kept by the study team while another set was kept by the participants. When participants expressed the need for more time to go through the study form, especially when they had little time for the meeting with the study team, they were allowed to keep the study information sheet for perusal and a subsequent visit was arranged. In one of the recruitment visits, the potential participant expressed the need to be assisted by his son, who would then approve of his participation or not. The son read through the study information sheet, presented questions to the study team, and when he was satisfied, he informed his father that he could participate with no concern.

The number of participants that was anticipated for recruitment in the study, as at the conceptualisation stage and as can be seen on the Primary and Secondary Participants' Information Forms (see Appendix 6 and 9), was not reached at the end of the study. This was because there was a good level of saturation reached in the finding of new theoretical links with the recruitment of each new participant. More so, the narratives and theoretical links discovered from the participants recruited were of such depth that they required further exploration. Hence, rather than seeking to attain the proposed number of participants, more focus was given to the development of the theoretical links and exploring the findings from the already recruited participants to avoid the production of redundant data.

## **2.4 Data Collection**

Data has been referred to by Bertram and Christiansen (2014, 71) as “the evidence or information that researchers collect in order to find answers to the particular questions they are asking” and it can take many forms. Data can be a set of results, statistics, interview transcripts or video recordings. This study made use of both secondary data, in form of published and grey literature, as well as primary data, in the form of collected data from conducted ethnographic fieldwork (see annexure 1 for secondary data collection procedure). Ethnography, as an anthropological research method, has been termed “the practice of writing about peoples” (Barnard 2000, 4). In order to gain knowledge about people and write about them in ethnographic research, a researcher spends time within the natural setting of his or her study. Doing this allows the researcher to observe and keep notes of the observed culture, beliefs and behaviours of the studied community. This form of research is also known as participant observation. An ethnographic approach and participant observation were used in collecting this study’s data, which was qualitative. DeWalt and DeWalt (2011, 1) defined participant observation as a research method whereby “a researcher takes part in the daily activities, rituals, interactions, and events of a group of people as one of the means of learning the explicit and tacit aspects of their life routines and their culture”. In doing this, the researcher is able to, as stated by Hancock and Algozzine (2006, 31), “observe and learn the patterns of behaviour, customs, and ways of life of a culture-sharing group”.

In this study, the researcher spent qualitative time being with and observing the lifestyles of the participants, both primary and secondary. I lived within the study community, sharing in the lifestyle of the community and all the available amenities (or lack thereof), seven months prior to and 12 months during the study’s data collection. The evening walks; moments spent watching young boys play soccer on roughly created football pitches and young girls playing in groups by the roads or outside kiosks; attending the traditional healers’ meetings; attending church services in in different churches in the community; to conducting visits to the clinics in the study community, all enabled me to observe the daily activities of the community in general. Aside from residing in the study area before, during the development of the study, and during the data collection and analysis, being a team member of the Bottlenecks Study, which was conducted at the same research site prior to this study, gave me an opportunity of spending considerable amounts of time observing and understanding the studied community, especially PLHIV and the primary health facilities. This time spent allowed me to gain some insight into the general lifestyle, norms and practices of the community, especially health beliefs and behaviours. It also allowed me time to become more in tune with the community, physically

and emotionally. After the recruitment of the study, qualitative time was spent with the research participants, within their residences or during their visits to their health providers, depending on their consent and comfort. Most of the time with the participants, however, especially the primary participants, traditional and faith healers, was spent in the homes of the study participants, usually with additional family members too.

This participation, however, was limited as I could not have actively taken part in every aspect of their daily lives, which also involved taking their medication, for primary participants, or being present during patients' consultations, for both secondary and primary participants. This form of participant observation has been described by DeWalt and DeWalt (2011, 23) as "moderate participation". They explained that in this form of participant observation, the researcher is present at the research site and is identified as a researcher; however, he or she does not participate actively or only participates occasionally but interacts with the people he or she is observing. This form of research is important as it gives the researcher room to observe for him or herself, while at the same time acknowledging and accepting the limitations of his or her participation, rather than depend on narrations without any personal verification. This form of research also contributes to the authenticity of the study as the researcher not only listens, but sees and feels what the participants share with him or her.

While ethnography and participant observation allowed me to be "correctly" positioned within the study setting, to observe and learn, further data collection tools were needed for the gathering of the direct data from the participants. The tools used were field notes and some aspects of grounded theory, such as theoretical sampling and open-ended interviews. Grounded theory, as an approach to data collection, was developed by Barney Glaser and Anselm Strauss over three decades in different publications together and individually from the 1960s in the Chicago school of symbolic interpretationism (Glaser 1978, 1992; Glaser and Strauss 1967; Strauss 1987). Although grounded theory is primarily a data-collection tool that allows for the development of theories, the approach was not utilised in this study for the development of a theory or theories. Some aspects of this approach were chosen because, as Corbin and Strauss (1990, 12) stated, grounded theory is a data collection method that allows for an in-depth approach to data collection and analysis, allows for open-ended interviews not guided by any form of structured or semi-structured questions, and gives room for deviation from the specific topic of inquiry. Such an approach, thus, allows for the collection of rich data, geared towards understanding and answering the study's key questions, as opposed to the development of a theory, which is, primarily, the purpose of grounded approach. As Corbin and Strauss (1990)



stated, the collection of data using the grounded approach and the analysis of the data allows for the discovery of concepts embedded in the data, but also the relationship between the discovered concepts through a process of analysis. This process, they said, is either for the purpose of theoretical development or explanation. Hence, the qualitative data collected in this study, through the use of ethnography and some aspects of grounded approach, were geared towards the explanation of the concepts discovered from the data and their implication and role in the plural health-seeking behaviour of the PLHIV in the study. Using this approach, all collected data are regarded as relevant to understanding the studied phenomenon. This form of research allows for flexibility in conducting open and efficient research based strictly within the collected data rather than based on the data within an already established theory (Charmaz 2003; LaRossa 2005). Hence, using certain aspects of the grounded theory approach, I was able to collect and analyse the study data simultaneously.

Fluent natural isiZulu-speaking qualitative interviewers, who were part of the study team, were always with the researcher during field visits. While the interviewers conducted most of the conversations in isiZulu, including the tape-recorded interviews, the researcher, who had basic knowledge of isiZulu, participated fully in the fieldwork. This was done during the observations carried out, conversations with participants before and after tape-recorded interviews, and the occasional responses made during interviews. After recruitment, during initial visits to participants, casual introductions and conversations helped to develop a rapport with the participants. At least two tape-recorded interviews were held with each participant, aside from the short visits to the participants, for either rapport-building, follow-ups for clarifications or sustenance of created relationships. As stated by Bernard (2011, 156), an interview can be regarded as a communication, which is in the form of a conversation between a researcher and a respondent. This form of conversation, however, differs from the everyday conversation as it has a set agenda designed by the researcher in order to probe a particular issue as a way of gathering information on that issue.

For the interviews, an aspect of grounded approach was used whereby participants were asked open-ended non-structured questions which ranged from their family history, life history, occupational history, health journey and general social views. This approach enabled the researcher to gain a better understanding of the participants, beyond the peripheries of their biographies. Before each interview, the interviewer reminded participants of the study and sought their consent to continue participating in the study and to be tape-recorded. Each interview was attended by a qualitative interviewer and the researcher, who often played an

observational role while taking notes for further queries. During the interviews, the researcher took note of the environment, activities around, the participant's looks, tone of voice and facial expressions while responding to the interviewer. After each interview, the researcher asked further questions for immediate clarification. The interviews were then transcribed and translated into English for immediate analysis and coding. On return from the field, debriefings were immediately conducted with the interviewer to allow synergy and alignment between the observations of the researcher and the views of the interviewer regarding the interview. Field notes taken by both the interviewer and the observer were then elaborated and compared for further alignment of findings. Where questions that needed further explanation by the participants were identified by the research team after each interview and analysis, a visit was scheduled and semi-structured questions were developed, as opposed to the open-ended discussions held in prior interviews. This process was followed and repeated in all subsequent interviews. All visits to participants were based on their availability and willingness. Refreshments were provided after each interview, not in exchange for the participants' participation, but as a sign of appreciation for their time and to replenish their energy.

A semi-structured interview is a method whereby a number of interview questions that have been prepared prior to the interview are used as a guide but not to be strictly followed as they remain open-ended and flexible in the course of the interview (Polkinghorne 2005). I used semi-structured interviews for this study as it allowed for a more in-depth discovery into the reasons behind the participants' use of plural healthcare services and the views of the health care providers regarding their patients' plural healthcare-use.

## **2.5 Data Processing, Coding and Analysis**

As a researcher, even before beginning to collect data, one usually chooses the details one is keen on collecting and collects these within an already chosen conceptual framework and research questions (Bernard 2011). This, however, was not the case in this study. This study made use of established theories as well as aspects of grounded approach in analysing the collected data. Data analysis, as Corbin and Strauss (1990, 13) stated "is the interplay between researchers and data. It is both science and art. It is science in the sense of maintaining a certain degree of rigour and by grounding analysis in data". It is also an art which requires creativity, which Corbin and Strauss (1990, 13) claimed, shows itself in researchers' ability to "aptly name categories, ask stimulating questions, make comparisons, and extract an innovative, integrated, realistic scheme from masses of unorganized raw data". This process of data gathering and

simultaneous analysis required finding a balance between science and creativity. This process of analysis involved narration, coding, interpretation and theorising the collected data through extreme creativity. To reach the abstraction level required in data analysis, Miles and Huberman (1994, 10-11) presented three stages that ought to be adhered to consistently in data gathering and analysis: “data reduction, data display and conclusion and verification”. Data reduction is “the process of selecting, focusing, simplifying, abstracting and transforming the data that appears in written-up field notes or transcriptions” (Bertram and Christiansen 2014, 116). The data was firstly reduced manually through coding, open, axial and selective. As Bernard (2011, 407) suggested, this process can take place throughout the period of the project, especially when a grounded approach to data collection and analysis is used for explanation of the studied concept. Hence the shift and transition through the different stages of coding was cyclical and non-linear throughout the study.

Corbin and Strauss (1990, 62) explained open coding as a process whereby “the data are broken down into discrete parts, closely examined, compared for similarities and differences, and questions are asked about the phenomena reflected in the data”. This process involved unwrapping and dissection of the data. In this study, this process occurred after each interview with each participant. The data collected from each of the interviews was broken down by noting the presence of *indicators* and highlighted for possible processing into *concepts*.<sup>18</sup> After the indicators and concepts of an interview were highlighted, a picture began to form, but there were gaps. Follow-up interviews helped to close these gaps and patterns emerged from the data of each participant. These patterns allowed for a good understanding of that participant’s health-seeking behaviour. This coding process was repeated with all participants until the health-seeking patterns of all participants emerged. A key step in this process was the testing of the early developed health-seeking behaviours through the concepts from the initially interviewed participants. This process is what LaRossa (2005) called axial coding. It is a process whereby categories, which come about from the merging of concepts across different participants, are related to their sub-categories, that is closely related categories or variables. These sub-categories, according to Corbin and Strauss (1990, 125), “answer the questions of ‘when, where, why, who, how and with what consequences?’” In this study, axial coding allowed the researcher to identify the similarities in the reasons behind the health-seeking

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<sup>18</sup> LaRossa (2005, 841) described the terms *indicators* and *concepts* as follows: an indicator refers to a word, phrase, or sentence, or a series of words, phrases, or sentences, in the materials being analysed. A concept is a label or name associated with an indicator or indicators; stated another way, a concept is a symbol or conventional sign attached to a referent.

behaviours of the participants as well as the motivations for these. This stage of coding enables the development of hypotheses on certain behaviours or practices, which are further tested in subsequent stages of coding and analysis. Hence, after the reduction of data, the data is displayed in organised and compressed format through thematic formation to enable the researcher to create links and discussions between the discussed issues, the questioned phenomenon and the existing theoretical frameworks. The next stage of coding, according to LaRossa (2005) is selective coding. This stage, he said, “entails the identification of a core variable. The core variable is one variable among all the variables generated during coding that in addition to other qualities, is theoretically saturated and centrally relevant” (541). Similar to LaRossa, Strauss and Corbin (1998) had also asserted that such a variable needed to have “analytical power” due to “its ability to pull the other categories (variables) together to form an explanatory whole” (146). As Glaser (1978, 95) stated, such a core variable has to have “clear and grabbing implications for formal theory”. It is from such a variable that the core findings of the study can be centred. Although all the streams of data analysis are interwoven and each is used at a different stage of the study, drawing final conclusions and verification was carried out as the last step of data analysis as collected information can change the meaning of the data before the end of the data collection and analysis.

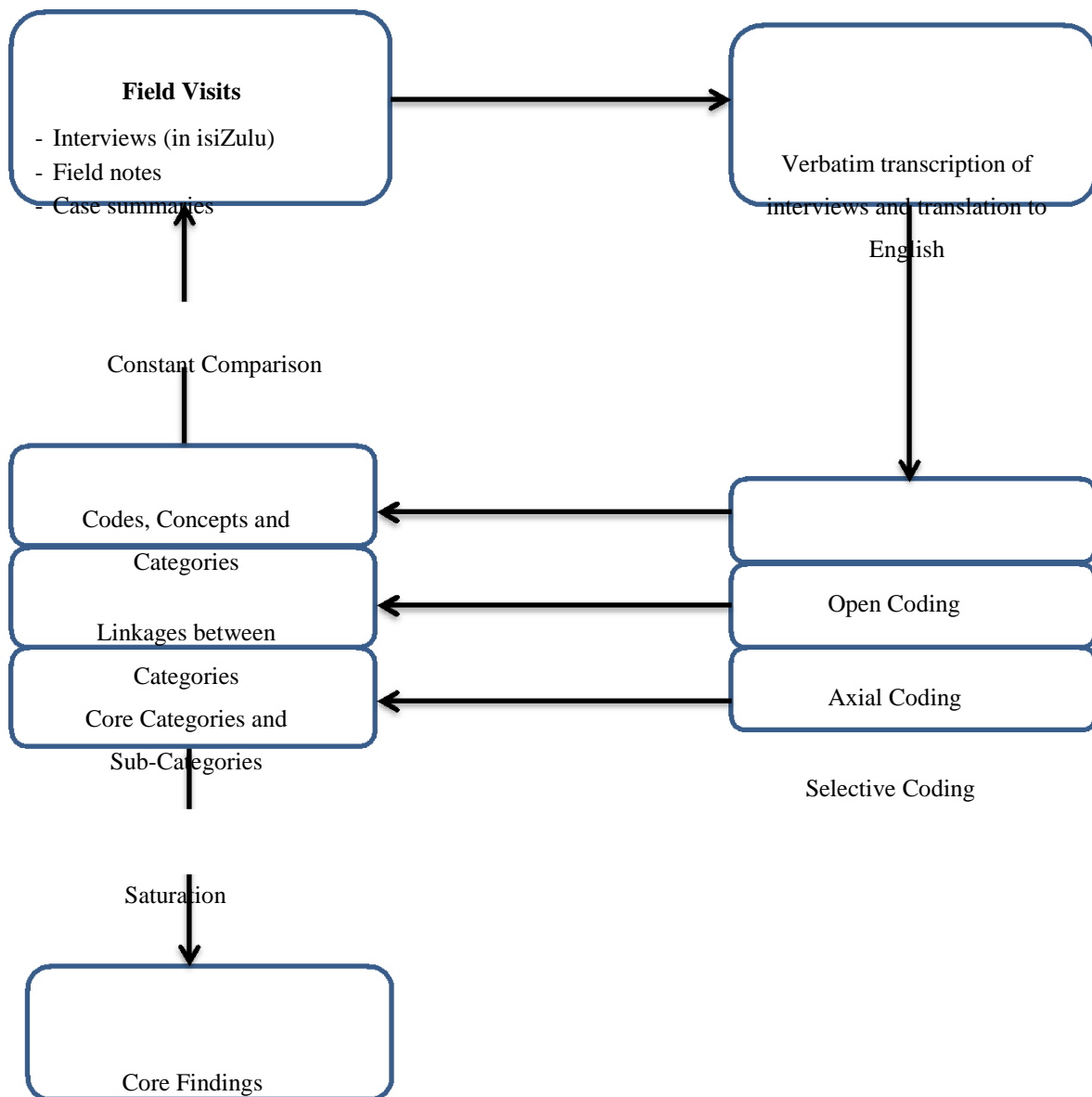


Figure 2.1: Aspects of grounded approach used in data collection and analysis. Adapted from Bezabhe et al. (2014)

## 2.6 Ethical Considerations

Ethics has to do with “behaviour that is considered right or wrong” (Bertram and Christiansen 2014, 65). In research, ethical conduct is of great importance, especially when the study involves people, animals or the environment. A researcher is expected to respect the rights of his/her research participants. Durrheim and Wassenaar (2002, 66) stated that there are three major principles that need to be observed by any researcher. These are: autonomy, non-maleficence and beneficence. These three major ethical principles do not only apply when fieldwork has started, but also from the process of developing the study protocol and in the report writing of the findings. Hence, to promote ethical principles guiding participants in this study, the study was firstly presented to the Culture Cluster of UKZN’s School of Social Sciences for theoretical and methodological scrutiny before it was presented to the host community, represented by the Community Advisory Board (CAB)<sup>19</sup> at AHRI, which was the host institution of the study’s fieldwork. The AHRI’s Community Advisory Board granted permission for the study to be conducted within the community without any issues or reservations (see Appendix 2.2 for CAB letter). Given the involvement of public health providers as research participants in the study and the Department of Health’s facilities being some of the study areas for recruitment and observation, the study was presented to the different Department of Health’s stakeholders for scrutiny and consideration. The study was presented to the ethics board of the Hlabisa Hospital, which was the overseer of the clinics that were to be part of the study. The study was also presented to the ethics committee of the uMkhanyakude’s District Department of Health and to the ethics committee of the KwaZulu-Natal’s Provincial Department of Health for ethical scrutiny. The protocol was approved by the different Department of Health’s stakeholders (see Appendix 3 for the Department of Health’s Stakeholders’ Gatekeeper Consent Letters).

After receiving ethical clearance and approval from the different community and Department of Health’s stakeholders, the study was presented to the ethics committees of UKZN, being the institution under which the study was academically registered. The study was presented to UKZN’s Social Science Research Ethics Committee (SSREC) and subsequently to the

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<sup>19</sup> This is a group of lay community men and women, both youthful and elderly from different walks of life, who have been nominated by the general community and recognised by the community head as representatives of the community with the organisation that hosted the study. This board conducts scrutiny of all studies to be conducted in the community, not only for their ethical sensitivity, but also for their clarity and benefit to the community. Until a study is certified by the board to be clear enough for the understanding of lay community members, ethically sensitive and beneficial to the community, it is not allowed to be conducted until the concerns raised by the board are rectified.

Biomedical Research Ethics Committee (BREC) as the study involved visits to the health facilities and contact with health providers and patients of such facilities (see Appendix 1.1 and 1.2 for UKZN’s ethics approval and recertification). Submitting the proposal of the study to the various research ethics offices was primarily for ethical scrutiny and to ensure that the study was within the appropriate and accepted ethical guidelines of the university and safeguarding the human rights of the participants and respecting the host institutions while generating credible knowledge. Full ethical clearance was granted before the fieldwork began (BREC Reference Number – BE005/16 – see Appendix 1 for ethical clearance form) and recertification was sought for the second year of the study. Gatekeeper letters were also sought from, and granted by the Mpukunyoni and uMkhanyakude heads of traditional healers to involve traditional healers within the community in the study (see Appendix 4 for the traditional leaders’ letters).

Before the study’s fieldwork began, the study team visited some of the clinics in the community which were to be part of the study to introduce the study and the team to the Operations Managers (OMs). The OMs of clinics which were later visited based on the links and their usage by the study participants were also visited and the study and study team were re-introduced to them before any field work began in the clinics. In the course of the study’s fieldwork, I was fully aware of the ethical principles and guidelines of research and adhered to them. Aside from my academic study of ethics and my previous experience of conducting ethically-sensitive research, my week-long training on ethical guidelines on Good Clinical Practice before the study and another two weeks of ethics training with the Global Health Bioethics Network (GHBN)<sup>20</sup> contributed to strengthening my ethical conduct throughout the study (see Appendix 5.1 for GCP certificate, Appendix 5.2 and 5.3 for the GHBN’s certificates). When recruiting, each participant was made fully aware of what the study was about as they were presented with the study information sheet, either in English or isiZulu, depending on their preference, and queries were adequately responded to (see Appendix 6 for information sheet). In doing this, they were also informed that their participation was voluntary and they could choose to withdraw from the study at any point without penalty. When a

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<sup>20</sup> According to the Global Health Bioethics Network web page, the networks is “a collaboration between the five Wellcome Trust Major Overseas Programmes (MOPs) in Kenya, Thailand-Laos, South Africa, Vietnam, and Malawi and the Ethox Centre at the University of Oxford” (Global Health Bioethics Network 2017). It is also a partner with the Wellcome Trust Brighton and Sussex Centre for Global Health Research, and aims to: promote and support ethical reflection within MOPs; carry out ethics research across the MOPs; and improve the capacity of the MOPs to identify and address the ethical issues in their own research (Global Health Bioethics Network 2017).

participant expressed a clear understanding of the study and the role they were to play, they were then presented with a consent form to sign, which were both English and isiZulu to accommodate either preference (see Appendix 7 for study informed consent forms). In cases where a person showed preference for isiZulu as a language, the assistance of a research assistant fluent in isiZulu was sought. The use of a translator at the request of a research participant helped to enrich the data as using a language natural to the participants allowed them to be more open and share more. While not all conversations with the research participants were electronically recorded, I however, sought their consent to use an electronic recorder during the semi-structured interviews and provided a consent form for this request. Using an electronic recorder enabled me and the interviewer to concentrate more during the discussion, a process suggested by Bertram and Christiansen (2014, 66). This was particularly the case for all the interviews in isiZulu (see Appendix 8). Only when consent was granted for the interviews to be recorded was audio recording conducted. There was no resistance from any participant for recording.

The autonomy of the study participants was also respected and guaranteed and I consciously avoided allowing my position as a Christian and also a sympathiser of TAM to shape my probing or analysis of their views and experiences of the different health systems. Through their own voices, the participants were able to express their autonomy in telling their stories. Hence, the participants' ability to self-express was practical in how they decided on when, where and how long to be interviewed, as well as who should or should not be present during the interviews or be aware of their participation in the study. They were often comfortable being visited even when there were other family members or friends present. This was despite the general fear within the research institute in which the study was hosted that community members are uncomfortable being seen with researchers from the institute as they would be noted as PLHIV.

Non-maleficence as an ethical principle means "no harm". As stated earlier, it is essential that the study respects and does no harm in any way to the research participants (Bertram and Christiansen 2014, 66), especially when the studied population is regarded as "vulnerable" within the codes of research ethics. PLHIV, who were the primary participants of this study, have been termed a "vulnerable population" (see Knickman et al. 2002). Vulnerability has been defined as the degree to which a population, individual, or a group of people is unable to anticipate, cope with, resist and recover from the impacts of disasters (Blaikie, Cannon and Wisner 1994) or susceptibility to harm or frailty, which is universal, regardless of location or



status, health, economics or social (Fineman 2008). The inability of the individual or group of people to cope with, resist or recover from unsettling circumstances or conditions, natural or otherwise, thus, makes them a “vulnerable population” and worthy of protection, a concept that is said to be traceable to the Belmont Report of 1979 (see Luna 2009, 122).<sup>21</sup> Vulnerable populations have been defined as individuals or groups of people “who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength or other needed attributes to protect their own interests” (Council for International Organizations for Medical Sciences [CIOMS] and WHO 2002, 64). Knickman et al. (2002) suggested such individuals were the economically disadvantaged, racial and ethnic minorities, the uninsured, low-income children, the elderly, the homeless, PLHIV, and those with chronic health conditions. The concept of “vulnerable populations” is thus built around the “dangerous cultures” or circumstances faced by some groups of individuals in society. These “dangerous cultures” or circumstances are often human induced, such as stigma, economic and cultural oppression. In some cases, however, the factors that heighten the vulnerability of individuals can be natural, such as disasters and diseases (Wisner and Adams 2002). How such “natural” circumstances arise, however, remains debateable, as human induced or not; hence Luna (2009) discussed the notion of vulnerability as a concept with layers. She stated that the notion is “relational” and “dynamic”. Commenting on Luna’s (2009) view on vulnerability, Lange, Rogers and Dodds (2013, 335) claimed that Luna (2009) asserted that vulnerability is relational “because it discovers each ‘layer’ of an individual’s vulnerability by closely examining the context in which she [or he] finds herself [or himself]”. They also stated that it is “dynamic” “because it recognizes that as the context changes, layers of vulnerability may come and go” (Lange et al. 2013, 335).

The dangerous cultures and circumstances around PLHIV, such as stigma and low access to health care that led to their categorisation as a “vulnerable population”, are thus fluid as there was a poor understanding of the disease and the illness experience in its early days, which is not necessarily the same in the present day. Hence, while PLHIV are often categorised as a “vulnerable population”, Luna (2009, 125) however, questioned such generalisations of groups

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<sup>21</sup> According to the United States’ Department of Health and Human Services (2018), “the Belmont Report was written by the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. The Commission, created as a result of the National Research Act of 1974, was charged with identifying the basic ethical principles that should underlie the conduct of biomedical and behavioural research involving human subjects and developing guidelines to assure that such research is conducted in accordance with those principles. Informed by monthly discussions that spanned nearly four years and an intensive four days of deliberation in 1976, the Commission published the Belmont Report, which identifies basic ethical principles and guidelines that address ethical issues arising from the conduct of research with human subjects.”

of people as a “vulnerable population” needing protection. She questioned whether vulnerability could be regarded as a category and if it is a “blanket concept that applies to all members of the group identified” (Luna 2009, 125). For example, she asserted that “although it is clear that all elderly people are elderly, and that very sick patients are all very sick, it is not equally clear that all elderly people are vulnerable or that all very sick patients are vulnerable, even if it is true that the elderly or the very sick may be vulnerable” (Luna 2009, 125). This view sets doubt on the notion that all PLHIV are vulnerable; hence some seek plural healthcare to avoid their vulnerability or need to be protected.

Nonetheless, at no point in this study was there any physical, emotional or social harm caused to the study participants. Although none of the research questions was intended to cause any emotional imbalance, participants were informed that they could have access to a professional psychologist (see Appendix 6 for information forms) who could counsel them in cases where they expressed some form of emotional imbalance due to the questions being asked. I also informed them that they could refuse to answer any further research questions if they felt uncomfortable at any time. The participants were also informed that a medical doctor was available if they needed to be attended to (see Appendix 6 for information forms), should they express any severe physical medical conditions in the course of the interview, be this due to the questions asked or not. The participants were informed that the data collected from the study could be used in publications or oral presentations, but their identity would be respected and kept anonymous through the use of pseudonyms. The participants were also informed that the data gathered from this study would be kept safe in memory sticks and folders that would be locked with passwords only accessible to the research team. This would be kept secure for five years after the fieldwork, as advised by the UKZN Research Ethics Office, and later destroyed through shredding and permanent deletion.

The last major research ethical principle is the principle of beneficence. This principle states that “the research should be of benefit, either directly to the research participants, or more broadly to other researchers or to society at large” (Bertram and Christiansen 2014, 67). This study will firstly be of benefit to the wider research community through providing an insight into the motivations behind the use of plural health care by PLHIV. This will be achieved by uncovering the mechanisms of how they use and negotiate these health services, hence knowing the types of services they receive and how they negotiate and place themselves within these systems. It will also be of benefit to the participants as this study will help give a voice to their experiences, plights and needs while making use of services from a plural health care

system. Knowing the experiences of the users of the existing systems will lead to the improvement and creation of appropriate HIV policies and services that address the health needs of such health users. As an immediate benefit, at the end of each interview, a combo or refreshment – a sandwich, a 250ml juice and a fruit were given to each participant.

The traditional healers were informed that this study would be of benefit to the participants and the organisation directly and indirectly. The study sponsored the hosting of one of the Traditional Healers' Organisation's meeting where they were to raise some of their worrying issues as well as research problems, such as the training of traditional healers in HIV care and recognition of their role in health provision, which they felt needed to be researched. The timing of this meeting was the decision of the organisation. The larger study, of which this study is a part, will further collaborate with other researchers from the Africa Centre to initiate an Action Research Programme at the end of the study. This programme will create room for dialogue between the different healthcare providers in the study brought together to discuss some of the differences between them and ways for better coexistence and possible collaboration. The participation of the providers in the forum will be voluntary.

Ethical considerations were also considered in the write-up of the thesis, which reports on the collected data. This is also known as intellectual credibility, a process where the findings are reported justly, accurately without bias or censorship, regardless of the levels of analysis. As this research took an interpretive approach, facts may not necessarily be in relation to general or universal notions of concepts or their understandings. Thus, facts in this study were the participants' thoughts as expressed in their assertions and actions, but also their feelings expressed at each particular time. As this research reports on people's personal experiences, to maintain credibility, during the analysis and write-up of this thesis, the researcher was conscious of questions such as "how well is the data reflective of the respondents' reality?", rather than asking if the data were facts or were true. According to Bertram and Christiansen (2014), it is the ability to respond to such a question in the affirmative that boosts the validity of the study and hence its reliability if tested in similar situations. Bertram and Christiansen (2014, 186) stated that reliability "is the extent to which the test, measure or instrument can be repeated with the same or a similar group of respondents and still produce the *same* (or very similar) results".

## **2.7 Study Limitations**

In conducting any research, there are always possibilities of shortcomings. The major limitations in this study were the unavailability of medical doctors to be recruited in the study and the researcher's lack of fluency in the local language used by the study participants, isiZulu. Although involving medical doctors was part of the conceptualisation of the study, this proved difficult. This difficulty arose mainly due to the absence of medical doctors in the clinics, who only visit about once a month and when in the clinics, they consult with an average of 34.2 patients. This unavailability of biomedical doctors in the study community made it difficult to involve them in the study.

There was also a possibility of bias in the views represented due to the high representation of traditional healers in the study, some of whom were amongst the primary participants and others among the secondary participants. Caution, however, was taken against such a limitation by openly and clearly capturing the views of other participants who had different health views.

The language challenge faced by the researcher prompted the use of research assistance so that interviews could be conducted in the natural language of the study participants, thus, limiting the active involvement of the researcher in the data collection process. A research assistant, whose fluency and efficiency in both isiZulu and English, was highly recommended by the Social Science Research Coordinator of the Africa Health Research Institute (AHRI). The skills of several research assistants were observed and tested in two weeks' training and interviewing, which included practical activities to test and strengthen research skills. Their ability to interpret, transcribe and translate texts from isiZulu to English and from English to isiZulu, were part of the tested and developed skills. Hence, all interviews were held in isiZulu, and the audio recordings were translated into English and quality checks were conducted by the Social Science Research Assistant's Supervisor, whose fluency in both isiZulu and English was highly rated at the institute.

The role played by the research assistants, both of whom were familiar with the study community, was vital to the study. One of the research assistants was a qualified teacher with vast experience of fieldwork for AHRI in the study community and the other had retail experience in public relations and interactions with non-familiar persons. With their qualities, the study team was equipped for the shortcomings of the researcher. The strong charisma of

both assistants and their ability to freely interact with participants in our first meetings always put participants at ease and they soon openly shared their life and experiences with us.

Due to the need to conduct interviews in isiZulu before transcribing and translating into English, there was a possibility that some meaning would be lost in the process of translation. This process of transcription and translation contributed to the length of time spent in conducting the study. This time, however, allowed for a deeper understanding of the data by the research team. This understanding was constantly shared by the research assistants who sought questions to some of the issues they found arising from the data even before completing the transcription and translations, thus allowing the team time to engage fully in not only the data collection processes, but contributing to the initial stages of analysis. This involvement in turn boosted their understanding of the study and their approach to subsequent field visits. Also, to limit possible loss of meaning, which was a factor that ought to be avoided in any study, if collected data are to be viewed with credibility, the research assistants took turns to verify each other's translations in relation to the original transcripts. Verification was also done between the original transcripts and the audio recordings to ensure that transcripts were accurately captured. This process aimed to ensure that the data was of high quality, credible and accurate.

The study methodology, although intended to enable a robust process of data collection and analysis, also had its limitations. This was particularly in relation to the time limitation that could have allowed for a deeper understanding of the study phenomenon using grounded approach and the development of a theory of medical pluralism. This limitation was also linked to the limited qualitative study approach. A longitudinal and more mixed approach has the potential of giving a more rounded view and understanding of the experiences of PLHIV using plural health care and its impact on their cascade of care as opposed to a shorter qualitative study. The number of participants, also, did not allow for general conclusions about PLHIV who use plural health. These shortcomings, however, were to be dealt with through the larger main study of which this doctoral research is only a part. The main study is longitudinal, involves more participants and makes use of a mixed method approach in terms of data collection. This study, however, focused on a limited number of participants to present an in-depth and accurate representation of their experiences and how they are able to negotiate the complexities encountered in seeking plural health care.

## **2.8 Principal Theories, Models and Frameworks**

Although theories cannot be regarded as panaceas, according to DiClemente, Crosby and Kegler (2009, 3), they do enable us to develop certain conceptual frameworks when choosing an important hypothesis that will influence a study. They help in providing some guidance in the manner of views held and expressions made around a phenomenon. Thus, theories were necessary for this study as they often serve as the guiding principles for a study across different disciplines, especially anthropology (see Barnard 2000; Creswell 2013; McGee and Warmes 2004). As stated by Grant and Osanloo (2014: 13), “without a theoretical framework, the structure and vision for a study is unclear, much like a house that cannot be constructed without a blueprint”. They are the windows through which the collected data in a study are understood, explained and interpreted.

Being a discipline mostly “concerned with understanding the ‘other’” (McGee and Warmes 2004: 1), anthropology and anthropologists make use of emic and etic research guided by certain established theories and frameworks in order to study people’s behaviours, beliefs and lifestyles. Theories have been defined as “interrelated sets of constructs (or variables), formed into propositions, or hypothesis, that specify the relationship among variables (typically in terms of magnitude or direction)” (Creswell 2013, 51). They illuminate the “grey” area in studied phenomenon as a way of linking and bridging the dotted lines that may be observed by a researcher. It could also be said that they help a researcher gain a clearer perspective on the phenomenon he or she observes in relation to established conceptions of society. In summation, the use of theories as stated by Grant and Osanloo (2014, 12), becomes the foundation on which knowledge is developed. In attempting to understand, explain and interpret the data collected in this study, two established social sciences theories and one health sciences theory were used in order to gain more understanding of the mechanisms of medical pluralism and the experience of users, especially in terms of how they negotiate the different services they receive as presented in the developed theory. The theories used in this study were Structural Violence Theory, Behavioural Theory and the Health Belief Model.

In the 1960s, a Norwegian sociologist, Johan Galtung introduced the concept of Structural violence. Galtung is renowned for founding the Discipline of Peace and Conflict Studies. At the heart of the Structural Violence Theory is the discourse on how “social structures – economic, political, legal, religious, cultural – stop, hinder or limit individuals, groups, and societies from reaching their full potential” or “the cause of the difference between the potential and the actual, between what could have been and what is... that which increases the distance between the potential and the actual, and that which impedes the decrease of this distance”

(Galtung 1969, 168). Galtung (1969, 106) stated that the concept of violence used here is in relation to the “avoidable impairment of fundamental human needs or... the impairment of life, which lowers the actual degree to which someone is able to meet their needs below that which would otherwise be possible”.

While PLHIV might have not suffered any physical violence for being HIV-positive, the lack of understanding between the service providers and the restrictions they receive can be regarded as a contributor to the impairment of the possible health services they would have otherwise attained if not for the rejection of some of their health behaviours. This form of violence, Galtung stated, can be termed “psychological violence”. He said this is a type of “violence that works on the soul; where the latter [psychological violence] would include lies, brainwashing, indoctrination of various kinds, threats, etc. that serve to decrease mental potentials” (Galtung 1969, 168). The complexity and tensions between the systems directly impacts on their level of comfort and ability to use the different systems at their best-chosen moments. As Gilligan (1996, 306) asserted, “Structural violence is often embedded in longstanding ubiquitous social structures, normalized by stable institutions and regular experience”. These structures can be regarded as the different guiding principles expected of the PLHIV using the health systems as well as the types of health services received by the PLHIV. Due to the nature of the guiding principles, health seekers are expected to adhere to the types of health care services provided, the established values of a system which are intended for a positive outcome can in the end become violent to its users. Such violence is inevitable when the holistic natures of the users’ needs are not taken into adequate consideration, yet they are expected to religiously follow established standards of a health system.

This theory was relevant to this study as it helped us in understanding how the beliefs and practices of the different health systems as societal institutions, individually or combined, become violent to PLHIV and their health. This violence was seen to take place at different levels. Firstly, it was through the oppression and rejection of some of the systems used in plural health-seeking by other dominant systems. Secondly, it was through the transfer of fear by dominant systems to users of plural health regarding the “risk” of using health systems other than the dominant systems. The oppression of one system of thought or health system over another can bring about tensions and violence not only between the systems but in and on the users of the different systems. As stated by Farmer (2004, 306), structural violence is strongly connected to social injustice, which is an “avoidable impairment” that reduces the degree of health that is otherwise achievable by PLHIV. This theory, thus, helped us unpack some of the

embedded beliefs transferred to users from the different health systems and how these beliefs and services shape the health-seeking behaviours of the PLHIV. Understanding how powerful health structures and views contribute in shaping the health-seeking behaviours of PLHIV allows us to begin to work towards changing the influence such structures and systems have on the health-seeking decisions of plural health users. Bringing this change is a call for us to begin to study the systems “not as we typically do, from the top down (systems to influence), but rather from the bottom up (experiences of individual users of the systems)” (Bevir 1999, 353). Taking the bottom-up approach allows us to place the users of the different health approaches at the centre of all health initiatives rather than working to change the health users to adapt to the prevailing health approach in the society. Being able to place the seekers of health at the centre of how health systems are operated, leads to *peace* in health-seeking and provision rather than the prevailing tensions and *violence*. Attaining peace, however, as Galtung stated, is the continuous negotiation of principles that do away with violence, which is a factor in increasing the gap between what a person can potentially attain to what a person actually has attained (1969, 168).

Another theory used in this study was Behavioural Theory. Behavioural Theory is a theory which asserts that humans behave in certain manners as a way of growing into a certain state of being or in order to gain a certain state or results. This notion has been explained by researchers (see, for example, Hennessy, Merro and Rathke 2003; Kelley and Michela 1980; Schultz 2004; Waelti, Dickinson and Schultz 2001) as an attribution of one’s behaviour or action to one or more causes. Such behaviours can either be personal or can be linked to cultural practices and rites. Behavioural theorists state that the developments of sociocultural systems are explainable through certain analogous principles. One of the principles is the Principle of Enculturation. Through this principle, people are able to live and adapt from one generation to the next through social learning and constant adaptation. As asserted by Alland (1973, 268) in an aphorism, “individuals die, new individuals are born, but culture lives on”. Each individual, with the normal learning abilities, is able to inevitably become a “carrier of certain sociocultural traits because he or she is exposed to the system of rewards and punishments, the contingencies of reinforcement, maintained by the members of a particular society” (Langton 1982, 341). The second principle held by the Behavioural Theorists is the Principle of Innovation. This principle states that the novel replication patterns of thought and action within a society develop in a random manner. Hence, “the selection of thought or action, whether positive or negative, is typically a function of the environmental consequences it generates” (Langton 1982, 341). This is also evident in Bandura’s (1977, 96) assertion that “behaviour is, in fact, extensively



regulated by its consequences. Responses that result in unrewarding or punishing effects tend to be discarded whereas those that produce rewarding outcomes are retained”. Behavioural theory is one of the well-known and often-used “attributive theories”.

Health beliefs, health-seeking behaviours and health practices have taken a range of forms and practices in different societies. Behavioural theory assisted me in understanding why PLHIV make use of plural systems – behaviour that has received much attention and criticism over the years in research on medical pluralism. The theory also assisted me in understanding and analysing the how/mechanism of medical pluralism, which are the basic steps taken by users in using and negotiating the services they receive. With understanding the mechanisms behind the negotiations implored by PLHIV in plural health-seeking, more light was shed on how PLHIV incorporate the different health services into their medical regimen and their aim and motivations for engaging in this practice. The health-seeking behaviours of the PLHIV in the study varied from one pattern of plural health to the other. Through behavioural theory, I was able to understand how and why the health-seeking behaviours of the participants varied and how such variations influence their well-being. All patterns, however, were seen to be as a result of the different health-seeking cultures developed by PLHIV in the different categories. The term ‘culture’ has been defined as the “transmitted and created content and patterns of values, ideas, and other symbolic – meaningful systems as factors in the shaping of human behaviours and the artefacts produced through behaviour” (Kroeber and Parsons 1958, 583). The behaviours of people, however, are carried out with hoped-for or expected reactions. As asserted by Kelley and Michela (1980, 358), the common idea behind peoples’ behaviours can be interpreted based on their causes and the reactions that can be discovered after the behaviour. Behavioural theory in this study aided in exposing not only the health cultures of the participants, but showed how their religious as well as traditional cultures contribute immensely to how they understand and approach health and illness, including HIV. Their behaviours showed consistency in wanting to attain a better state of health, thus expressing their agency and resilience in surviving the rather complex system of medical pluralism, which exists in the face of tensions and challenges to primary health care delivery in the study community.

Embedded within the debate on behaviours and action is the notion of agency. This debate is on the question of what shapes people’s behaviours as contended by the behavioural theorists. Agency as a word is derived from a Latin word *agentia*, which is an abstract noun of another Latin word *agentem*, meaning “effective” or “powerful” and it is the present participle of

“agree”, which means “to set in motion”, “to drive forward”, “to do”, or “to perform”. The word was used in the 1650s to mean “active operation”, and in the 1970s as “a mode of exerting power or producing effect” (Online Dictionary Etymology 2018). Rapport (2004, 1) asserted that the word pertains to the debate on the “relationship between individuals and social structure” and “to the nature of individual consciousness, its ability to constitute and reconstitute itself, and ultimately, the extent of its freedom from exterior determination”, in other words, becoming creative. This process of self-reconstitution is made of human actions, which Max Weber emphasised, spawns from rationality: consciousness, reflection, intention, purpose and meaning. This view however, has been noted by Rapport as a liberal stand towards “agency” as there is a communitarian view, with the French sociologist, David Émile Durkheim as its founding father, which holds that human creativity operates only within the bounds in which already developed social structures allow, and is thus restricted (Rapport 2014). Indeed people’s actions are carried out within existing structures; this, however, does not take away the conscious effort made to creatively act or navigate through the existing societal structures.

Although the existing structures may result in constraint decisions, these structures do not necessarily take away the power of conscious decision-making of individuals or dictate what actions individuals make. Societal structures, as they are, are developed by people and continually evolve over the years. This process of evolution is a result of how individuals engage with the structures, mostly, how the existing structures are constantly recreated through the use of individual creativity, which is an expression of agency. This recreation of society, Leach (1977) held, is because agency is the display of a deep-seated desire inherent in humans to act against established societal rules as a way of generating new ones. He stated that “all of us are criminals, born by instinct. All creativity... contains within it a deep-rooted hostility to the system as it is” (1977, 19). Sharing Weber’s view, however, I hold that this desire to recreate society is systematic and conscious, not necessarily instinctive. The debate on the recreation of social structures as a conscious human effort has been widely discussed in literature. Lavie, Narayan and Rosaldo (1993, 5), for example, stated that creativity is “human activities that transform existing cultural practices in a manner that a community or certain of its members find value”. Also, Giddens (1976, 15) stated that “while not made by any single person, society is created and recreated afresh... by the participants in every social encounter. The production of society is a skilled performance, sustained and ‘made to happen’ by human beings”. Thus, regardless of which view one holds of agency, the concept as related to this study pertains to how the study participants were able to consciously make goal-oriented

health-choices despite the social structures, rules or requirements on them from the health systems they use, to develop new pathways to seeking health.

Behavioural theory also allows us to understand how the study participants withstood the complexities they faced while seeking and developing new health pathways. In withstanding the complexities of using a plural health system, the participants displayed a high level of resilience in expressing their agency in making their health-choices, despite the opposition of some of their health providers. Unger (2008, 26) defined resilience from three dimensions. He said resilience is "... the capacity of individuals to navigate their way to resources that sustain well-being", "... the capacity of individuals' physical and social ecologies to provide these resources" and "... the capacity of individuals, their families and communities to negotiate culturally meaningful ways for resources to be shared" (2008, 26). These definitions, he said highlight "the need for individuals to exercise enough agency to make their way (navigate) to the many resources they require to meet their developmental needs. These resources must be both available and accessible. They range from psychological resources like feelings of self-esteem and a sense of attachment to accessing health care, schooling and opportunities to display their talents to others". Rak and Patterson (1996) stated that emphasising resilience increases the attention paid to strengths and reduces the emphasis on pathology. This effort has also been highlighted by O'Leary (1998, 426) who stated that "psychologists have recently called for a move away from vulnerability/deficit models to focus instead on triumphs in the face of adversity..." Thus, he went on to assert that "the potential theoretical, empirical and policy significance of the proposed paradigm shift from illness to health, from vulnerability to thriving, from deficit to protection and beyond, ought not to be underestimated" (O'Leary 1998, 426).

To aid in the understanding of the collected data and their analysis, the Health Belief Model was also used. Our understanding, socially learned or self-engineered, of society and its structures play a role in how we construct and understand health, health practices, and how we interact with health services. A theoretical background to this form of understanding is the health belief model. This model of understanding people's health beliefs and practices is a systematic explanation and prediction of preventive health behaviour. This theory was developed by Godfrey Hochbaum, Stephen Kegels and Irwin Rosenstock around 1952. This theory strives towards unpacking people's health behaviours and motivations as a way of "distinguishing illness and sick-role behaviours from health behaviour" (Hochbaum, Rosenstock and Kegels 1952, 1).

This model was vital to this study as it aided me in understanding some the beliefs behind the use of plural health care systems by PLHIV and how such motivations shape their general health beliefs. Hochbaum et al. (1952, 2), in constructing this analytic model, were of the belief that this theory could enable researchers to predict and understand how people's health behaviours have been constructed and maintained by their belief towards prevailing health systems and practices. As this study does not only seek to understand the beliefs and motivations behind the use of plural health care systems by PLHIV but also how they interact with these systems, this theory assisted us in creating the link between the beliefs and health practices of the research participants. The theory allowed me to understand the various health beliefs and understandings held by the research participants. Such beliefs ranged from how they traditionally view health and illness and how such views are forced to change when they interact with the biomedical health facilities, and how they view their use of plural health as not only a health-seeking process, but as a way of asserting their power of choice rather than conforming to dictated dominant norms.

The three theories used in the study shaped the conceptual approach of the study. The theories were all linked, build on each other and offer different contributions to the understanding of a phenomenon. Theories often do not singularly fully provide the conceptual guide needed in understanding a phenomenon. Due to this, researchers often adopt different aspects of different theories in developing conceptual frameworks when exploring a phenomenon. Firstly, the health belief model shows how the participants in the study had different health beliefs which spur them to using different patterns of health-seeking, thus expressing their health behaviours. However, their health behaviours are not necessarily independent of interference. The plural health system in which they operate is riddled with complexities and tensions between the different systems used. These tensions often play out violently to the users in their journey of health-seeking. This form of violence is somewhat embedded in the health structures in the society and how they are practiced. These structures, due to their different founding principles towards health and illness, can lead to the users being torn apart in discomfort and uncertainty in choosing when and how to use what health approach. The subsequent self-chosen health routes of the participants in complex health system, which arise from how they are able to navigate the different systems, are expressions of how they adopt certain survival behaviours. These navigation mechanisms of what is often seen as a "dangerous" and complex system of health practice, portrays their health behaviours, which are not only shaped by their health beliefs, but also by the existing factors in their health seeking. The adoption of this conceptual framework provided an approach as to how the research problem was to be solved. Grant and

Onsloo (2014, 16) implied the development of a conceptual framework shows a researcher's understanding of not only how the research problem will be solved, but also an understanding of "the specific direction the research will have to take, and the relationship between the different variables in the study".

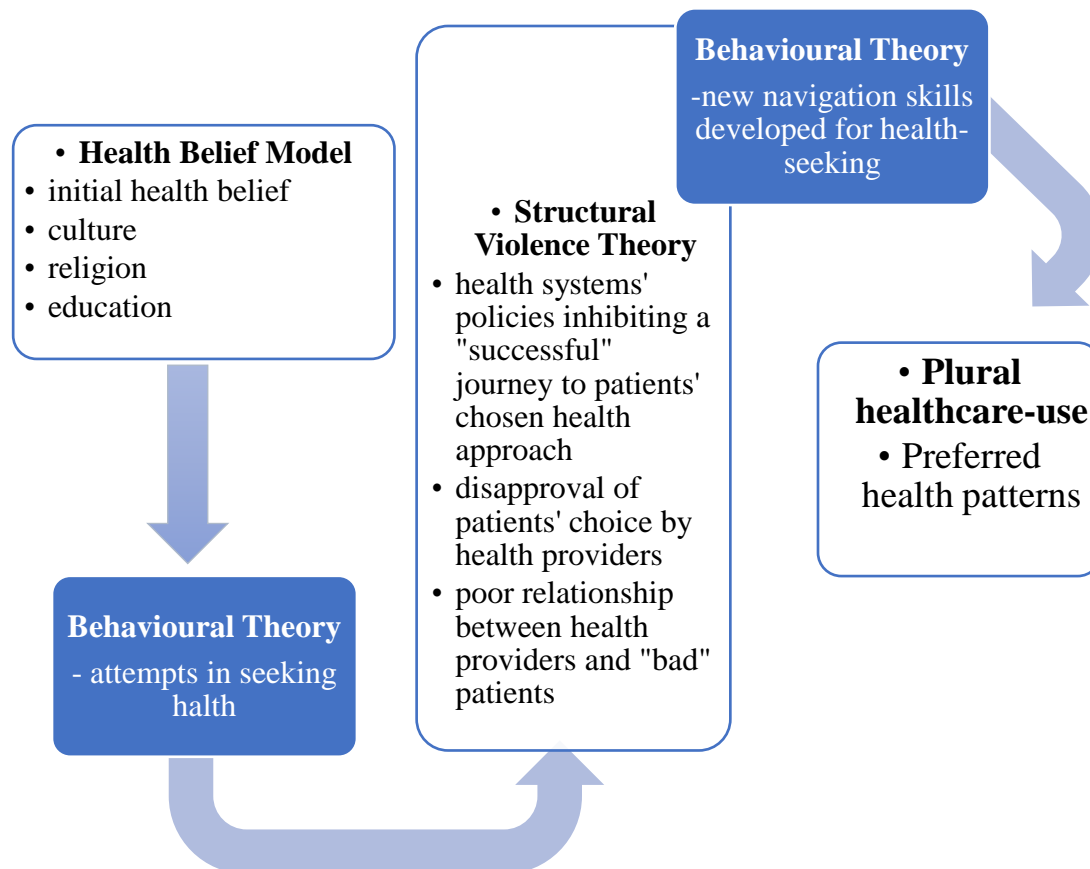


Figure 2.2: Health seeking journey: conceptual framework

## 2.9 Conclusion

The exploration of chosen phenomena by answering identified research questions can be regarded as an adventure. This process allows us to make sense of some aspects of the world through the research of a phenomenon, as stated by Bertram and Christiansen (2014). The use of guiding aids, in the form of research tools, methods, and frameworks, not only aids in creating order for a systematic data gathering and analysis, also allows for a coordinated presentation of the collected and analysed data.

This chapter looked at the different tools used in this study, how they were used and the justification for their use. The chapter presents some details about the study community, the

manner in which the study participants were recruited, the approach to the data collection and analysis while considering the necessary ethical guidelines. The chapter also presents some of the challenges encountered in the course of the study and how such challenges were mitigated in order to attain high quality and credible findings. The principle theories and frameworks used in the study were another key aspect of the study looked at in this chapter. These theories, which served as windows through which the data was viewed, interpreted and presented, were fundamental in the understanding of the experience of PLHIV who were plural health users within a wider societal context. This context, which is made up of different institutions and beliefs, contributes to how PLHV make health decisions and behave. The presentation of these different aspects of the study presents readers with a clear map of how the study was conducted and how the findings were reached.

## **CHAPTER THREE**

### **Use of Multiple Health Approaches by People Living with HIV: Intentions and Reasons for Plural Health-Seeking**

#### **3.1 Introduction**

Defining and understanding the concept of health conditions or illness varies, depending on what health model or philosophical and ideological approach a person uses. When having a disease or being ill, one is said to be sick. Hahn, an American epidemiologist and anthropologist, for example, defined sickness as unwanted conditions of self which, to some level, pose a threat to a person (1995, 22). As a result, the threat may be, according to Brown, “a clinical phenomenon, defined by the pathophysiology of certain tissues within the human organism” (Brown et al. 1998, 11). This threat can also be the vivid experience of pains believed to have been caused by a neighbour’s spiritual influence, the ancestors or God’s way of passing a message or reprimanding a person (Brown et al. 1998; Chigona et al. 2008; LaMeaux, 2015; Naidu 2014; Parle 2003; Richter 2003; Valenkamp and Van Der Walt 2006). Whether regarded as a disease or an illness, the participants in this study experienced different health conditions, through which they sought plural health. The participants often sought healing from different health approaches, depending on the health condition and their understanding of the condition.

The use of plural health amongst people living with HIV/AIDS has been shown to be prevalent, globally (Micollier 2004; Pawluch et al. 2000) and in Africa (Nagata et al. 2011; Peltzer et al. 2008; Tocco 2010). In South Africa, for example, Peltzer et al. (2008) showed that many ART patients resort to traditional medicine due to the side-effects of ART or other HIV related symptoms. Such use is also seen in Pantelic et al. (2015), in a study with 2 477 parents or primary care givers in some rural and peri-urban areas of KwaZulu-Natal, South Africa. A sub-sample of 435 of the 2 477 participants was identified as needing ART. Of these 435 participants, 20% were reported to be users of plural health. With more openness in disclosing the use of plural health, such percentages are likely to be higher. This is likely to be the case as cases of plural health use are sometimes either not detected by health care providers or are not reported by the plural health users. Such non-disclosure has been said to be mainly due to the negative reaction meted on plural health users by some health care providers (see, for example, Baer 2008; Baer 2015; Ennis 2014; Marwick 2005). Plural health practice by people

living with HIV, like amongst people with other health conditions, involves the use of different health systems. The case of a patient in Moshabela et al. (2011, 846) is one of these classic scenarios. In this study, Moshabela et al. documented how Mabuti, one of the study participants, sought health from different health approaches and providers in his HIV health-seeking journey. In the study, the health-seeking journey of the participant was seen to take about four years between having symptoms of HIV to eventually being initiated on ART. This use, as literature has shown, is a complex web which does not have a standard operation procedure guiding users as to when to visit what system and with what health conditions. The “rules” of the practice, when and where they seem to exist, are often fluid, mostly depending on user’s health view, but also on the health condition suffered. Thus, this chapter focuses on exploring the health systems used by the participants and the drive they had towards the use of each of the health approaches.

### **3.2 Use of Biomedicine by People Living with HIV**

Despite the existence of many health systems in the study community, the participants in the study all made use of the biomedical health approach. The use of biomedical health facilities by the participants was for both HIV care and the treatment of other biomedically-related and understood health conditions. For most of the health conditions reported by participants in the study, especially conditions that the participants believed were treatable biomedically, they sought biomedical assistance in clinics or hospitals, except when they had an understanding of the illness that differed from that proffered by biomedicine. The use of a health system by the participants was a sign of their health knowledge and how this shapes their health care seeking behaviour.

One of the major streams of biomedicine used by participants in the study was the clinic. As the clinics have been structured by the Department of Health to be the primary health care centres in communities and the most available and accessible biomedical health facilities, they were often the first point of contact most participants had with the government’s health care facilities. Some of the participants in the study reported to have only started making use of the clinics as adults. This was because when they were younger, there were either few accessible clinics in their communities or their parents were staunch believers and users of other health practices, hence did not make use of the clinics. Some of the participants, however, began using the clinics from their childhood, even though the clinics were not in close proximity to their homes, they were able to make regular visits to the clinics for different health conditions. One of the participants stated:



*I use the clinic because it is the clinic which refers me to the hospital if there is a need to go to the hospital and that depend on the fact that I am very sick (Sifiso).*

One of the participants who always made use of the clinic, stated:

*I was not initiated on treatment, my CD4 count was high, and I only took the pills for prevention for the child, yes. I continued checking my CD4 count and the child was taking her treatment. I have [also] started. I am taking it [ART] since last year 2015 July. I normally use the clinic. (Nobuhle)*

Nobuhle was one of the participants who said they had found a very good need to always visit the clinic whenever they had any health need, especially in maintaining a “proper” regimen for their ART. This choice to make use of the biomedical health facilities is in line with the general requirement from biomedical health practitioners to PLHIV, who are always advised to constantly make use of the facilities for all their health needs, especially HIV care. Her health choice of always making use of the clinic was strengthened when her father and sister passed away as they did not make “proper” use of the clinic, especially her father.

Another participant who showed dedication in using the clinic despite being a traditional healer was Nolwazi, who has maintained an active ART programme for about seven years. She spoke highly of the need for all those living with HIV to maintain an active ART adherence and a healthy lifestyle. This view, she said, she also passed on to people whom she trained to become traditional healers, especially those who are HIV positive. Living close to the clinic, she is well known by the clinic staff as she had been an active user of the clinic even before she tested positive for HIV. She is also one of the reputable traditional healers in the community.

From the narratives and the participants’ use of the clinic, it can be seen that although there are other health approaches for treating other illnesses or health conditions, the treatment of HIV was limited to the biomedical health system. This was because the study participants clearly felt and accepted that HIV/AIDS can only be treated biomedically. Some were aware of certain instances where traditional healers had failed to treat HIV/AIDS which contributed to their confidence in biomedicine.

HIV testing and treatment was the main reason the participants to use the clinics. Due to their knowledge of HIV/AIDS and way in which it can be treated, most of the participants were positive towards treatment when they discovered they were HIV positive.

*I didn't have any stress I just say just because I know that I'm infected that is my wellness. Because father [husband] was sick for a long time, that means he was infected a long time ago. Yes he was a cheater but I didn't feel bad that my husband went around the world and came back and infected me. I just said to myself I also touch people who are infected if they are here it can happen that I am the one who infected him. So I didn't know I just accepted it. (Nolwazi)*

*I found out I was HIV [positive] in 2013. It was painful but I thought it was life and that it will go on, the child will live and I will be if I continue with the ways (health practices) I was taught at the clinic. (Nobuhle)*

Despite being believers and users of multiple health systems before and after being HIV positive, most of the participants expressed immediate acceptance of their HIV status when they first tested positive despite the shock. Some of the participants asserted that this willingness to engage in treatment was due to the counselling received from the HIV counsellor, but also because they had partners who were already HIV positive, hence were prepared for a similar outcome. The attitude of the participants resonates with that of many members of the community who are seen to be actively on ART. The role of HIV education received not only from the clinics, but also from health research institutes such as AHRI was highlighted by the participants as contributing factors towards their acceptance of their HIV statuses and understanding of how to manage their experience of living with HIV. While some of the participants immediately accepted their HIV status and treatment in the clinics, others initially rejected their HIV status and the treatment offered.

*After testing positive I saw that it was hard and I could not accept it because I didn't think it was like this. They made me a transfer letter to go to whichever clinic I could afford to go to. I then went to the [name of her local clinic] and I was accepted. Being educated there made my heart accept and I even felt accepted here at home. I have accepted it now because I have been going for my CD4 count right here at the mobile [clinic]. (Lindiwe)*

Although Lindiwe initially rejected the fact that she was HIV positive, she later accepted her HIV status and made adjustments towards a life of living with HIV. Her initial rejection, however, was not due to her belief in traditional healing, but due to the shock of finding out that she was HIV positive, especially considering that she was a teenager at the time. Since the acceptance of her HIV status however, she has maintained an active ART programme throughout her HIV journey, despite being a traditional healer. Lindiwe's immediate response is similar to that of many people who discover that they are HIV positive. This is the case, as stated by Kelly et al. (1998), because often people are unable to envisage themselves as becoming HIV positive, regardless of a risky lifestyle. Therefore, the trauma of this knowledge can leave people depressed or in denial. However, the counselling and health knowledge of the participants enabled them to make use of the clinic for their HIV care, despite the initial shock. There were other participants, however, despite their knowledge of HIV and the awareness of the available treatment in the clinics, chose not to take on treatment after finding out they were HIV positive. Although the study participants use the clinics for the treatment of illnesses such as TB, diabetes, asthma, epilepsy and body pains, the most common use of the clinics amongst all the participants was for either HIV testing or treatment, as most of the participants participated in ART in their various clinics. One of the participants, who was not on ART, stated that he was "cleansing" himself using traditional healing before going back to the clinic. He said he was taking this as the nurses had informed him during his diagnoses that his blood was dirty. The second participant not on ART, was a traditional healer who was unhappy with how he was treated by the nurse at the clinic when he was diagnosed of HIV.

*After testing positive, they said I must come back on Monday, but I didn't go back. No, I was afraid (laughed). Ey I was just shocked. They tried to give me counselling but I didn't think what they were saying was that serious because what they told me was confusing. I believed the results, the machines won't lie, but what was confusing me was the way the nurse talked to me. She said "you see now, you will stop (laughing) saying it's the ancestors now you see that you are sick". She just used what she saw on my body (the traditional healers' beads). What she said didn't sit well with me, but I just got over it because nurses are disrespectful, I know. I got out and left, but I was shocked, yes I was afraid, ya I am afraid. Now that I know the result, (laugh) I don't know, but I need to visit the clinic, it's just that I don't feel any pain in my body. I won't take any action as... I am afraid but I will go, I have to force myself to do it, but I am afraid of the nurses. (Nkosinathi)*

Nkosinathi's refusal to begin treatment was mainly due to the nurse's reaction after he tested positive with HIV. The nurse pre-empted the possibility of him claiming that he was only HIV positive due to some ancestral role in his life and rebuked him for this. This discouraged him from beginning his treatment. While the practice of medical pluralism may be, and is often, regarded as a barrier to the progression of PLHIV on their cascade of care, the attitude of their health care providers, especially biomedical, may be a greater barrier. This is so because the practice, per se, does not necessarily hinder the plural health users from engaging and seeking health care from the biomedical health facilities, as seen in the case of Nkosinathi. Instead, the negative reactions to the users' plural health practice by their biomedical health providers often serve as a deterrent and put people off visiting or utilising the biomedical health facilities. In addition to Nkosinathi, Mqondisi also accepted that his blood was "dirty", a phrase often used by nurses to mean that a person is HIV positive; however, he opted to "cleanse" the "dirty blood" traditionally, rather than biomedically.

*I did all the tests when I was having TB for the second time. I said to the providers to do all the tests and they said my blood was too dirty... they said that they didn't find any TB but the result said my blood is too deoxygenated.*

*After I arrived at home I went to [name of a clinic close to his home] and they also did the tests, same time they said my blood was not right and they asked if I was using any traditional medicine and I said yes. And they said "okay we should have given you the pills but if you have herbal mixture that you are using then you can carry on using it.*

*I don't know what pills those were, even now. I wish to know but I was waiting for them to tell me that as I said I'm taking herbal mixture, "you must come back to do the retest to see if the blood is improving or not so that we will give the pills for your illness" because if the blood is dirty there is no illness that you will not suffer. (Mqondisi)*

The understanding of HIV to mean that one's blood is clean or dirty was highly influential in the participant's resorting to traditional healing for "cleansing" of the "dirty blood". While in our encounters with Mqondisi, he showed an understanding of what HIV was, there was no clarity as to whether he understood that he was HIV positive or not as he continually referred to his HIV status as "dirty blood". In consultation with his biomedical health providers, the

study team discovered that he was due to be enrolled on ART after his second visit to the clinic, however, he did not return to the clinic. Instead, he informed the study team that he was still consulting his traditional healer to attempt to clean the “dirty blood”. Mqondisi said he would only return to the clinic to check his “blood status” after completing the different ritual procedures he was involved in to clean the blood. His actions seem to be in line with his understanding of the conversations he had with the nurses in the clinic. He said:

*They said “no you can continue using it (traditional medicines), if you see that you have tried everything and it’s not helping then you can come back to the clinic to take treatment”. I just said I will hear from you which pills I will come and take if I am not feeling well. I just take traditional medicine. Since then till today it’s just flu that makes me cough only, nothing else that makes me suffer.*

While Mqondisi’s assertions may appear at odds with what is regarded as the “normal” recommendation from nurses to patients who are diagnosed with HIV, the experiences of other participants in clinics were similar as to how the nurses responded to them – condescendingly – if they are aware of their use of plural health. They reported that some of the nurses often angrily said to them they could keep using their traditional medicine instead of ARVs to see if it helps them. This response from the nurses however, as later discovered in our interviews with the nurses, was not because they approved the use of traditional medicines in place of ART.

Instead, it was because they believe that the patients are “too stubborn” by wanting to make use of traditional medicines while on ART even when they, as nurses, warn them against such a health-seeking approach. To the nurses, however, both treatments should not be taken concurrently as there are likelihoods of counter-indication. Within the differing manners in which the nurses and the patients approach treatment adherence is often a misunderstanding of the intentions and actions of the patients from the nurses. The patients appear not to necessarily intend seeking a cure for their HIV from other health approaches, as assumed by the nurses; rather, they often utilise these systems to treat health conditions they believe are treatable within such health systems or conditions they believe paved the way for their HIV positive status, such as in the case of Mqondisi. These differing views, in most cases, can leave patients feeling constrained, especially as the power dynamics in the relationship with the biomedical health practitioners is not on the same level and the providers often hold the higher grounds of power in the relationship. Such attempted restrictions can be regarded as a form of

psychological violence towards the patients, their beliefs as well as their health-choices. The effects of such psychological violence towards the patients, however, contribute to pushing them towards making a choice between using one health approach over another. Such a reaction from the nurses, in line with Galtung's view on structural violence, can be "the cause of the difference between the potential and the actual, between what could have been and what is... that which increases the distance between the potential and the actual, and that which impedes the decrease of this distance" (1969, 168). This is so because the nurses' response to the patients increases the distance between the actual state of health of the patients and their potentially improved health. For some patients, however, such a choice is not to be made as they prefer to use both health approaches, not choosing one over another. However, when a choice is made, their default health approach becomes the chosen approach, as in the case of Mqondisi, thereby expressing their agency, albeit constrained, in finding health peace and harmony regardless of the existing structure and experienced violence.

Within the context of biomedicine, the hospital was widely used amongst the study participants. Although most of the participants reported using the hospital at different stages of their different health conditions, Cothoza had multiple and prolonged visits to the hospital when he had a swollen stomach. Due to the hospital's failure to diagnose and treat his condition, he went on to visit other health systems. However, he still returned to the hospital for check-ups and for his final treatment, which saw the end of the swollen stomach. The hospital, for most of the participants, was only utilised when facing major health conditions that were not treatable in the primary health facilities. Aside from the lack of need to constantly visit the hospitals, the distance of the only hospital in the sub-District made it difficult to be utilised by the participants in the study. Nonetheless, when there was a need or when referred to the hospital by the health providers at the primary health centres, the participants were not hesitant in using the hospital.

*I came to the hospital and they checked and tested me there. They got everything about my health then they said that it was this thing the... the Tuberculosis. Then when I started taking this treatment, the TB treatment, ooh there was the stomach. It became big. It was like a mountain eeh. I was asking myself then that ooh what was happening. I went back there; they kept trying to drain this water. Well they drained that water and it came back again. They didn't know it was the liver. (Cothoza)*

Some of the participants also made visits to pharmacies while seeking health care. While seeking treatment for his swollen stomach, Cothoza experienced flu, a health condition that is easily associated with the changes in the country's weather.

He said:

*I was just myself, feeling just fine then I noticed that no this flu now I was trying this and that but no, then I went to buy pills at the chemist for flu, flu mix from the chemist. I was trying them taking them but I ended up going to the clinic.*

The frustration of seeking health from different health providers was rife in Cothoza's health journey. He was often disappointed with the inability of the different health providers he sought help from to heal him from the various health conditions he had experienced. Hence, going to the chemist was one of his resorts to seek health when experiencing flu. However, with the flu being an opportunistic infection that persisted due to his possible high viral load, he ended up going to the clinic for help. This assumption about his viral load was confirmed when he said, "*they also took blood and did everything then they found out that the CD4 count now was not good, it was low. I had to start this thing (taking ARVs)*".

Another participant who was familiar with the use of medicines from the pharmacies was Mkhumbuleni who spoke about medicines such as *The Beauty Zone* and *Skhwili nobhoko*, or "*to look for the painkillers only*" if he had flu. The same could be said of his partner, *Nobuhle*, who said, "*I use muthi from the pharmacy for cleaning gall juices which you take the whole bottle at once*".

The use of pharmacies and chemist was not peculiar only to the group of participants who were not traditional health practitioners. One of the primary participants, who was also a traditional health practitioner, reported using the pharmacy, where he buys some medicine for body cleansing:

*No I only use that (the chemist) if I want to clean myself like iziwasho it's the holy water with the lucky stone bought from the pharmacy. I used to buy them from the pharmacy in town than I came back and mix it. (Nikhil)*

While Nikhil made use of the medicines from the chemist and was also a dedicated user of the clinic services, especially for his ART and other treatments, he said he tries to make the best

use of any health approach that he finds helpful and mixes it with traditional medicines, if necessary.

While many of the participants made use of clinics and hospitals when needing treatment for most of the health conditions they suffered, some participants (who were able to afford it) also made use of private doctors. Cothoza stated how he received treatment from a private doctor, one amongst the three he had visited.

*The doctor treated me, from there then said no the stomach is full of water.  
“Ok since you have water in the stomach let me give you the referral letter to  
the hospital”, said the doctor. He made me the referral letter to hospital.*

The use of private doctors, however, was often aligned to people with a stable or economic status. Such people, who have stable sources of income, often make use of medical aids to fund their medical bills, thus, are able to avoid going to the government clinics and hospital whenever they want to. As stated by Lindiwe: *I would use a doctor most of the time because by that time I was still under the medical aid so we would use a town doctor. (Lindiwe).*

The use of biomedical health facilities was common amongst the participants of the study as they regarded some of the illnesses they experienced as “biomedical in nature”. Some such illnesses had already been treated as at the time of meeting the participants while other illnesses were still being treated. These health conditions were viewed as “biomedical” by the participants because they believed that such conditions are “officially” researched, explained and treated within the biomedical sphere. This view had been gained from health awareness programs and clinic visits. Hence, with conditions categorised as ‘biomedical’, the participants were convinced that they needed biomedical assistance, even when they might have, in the end, used other healing approaches in alternation or sequentially and even concurrently, for the conditions. The use of the different biomedical health practitioners was viewed differently by the participants. High regard was often given to the formal systems, clinics and hospitals, regulated by the government’s Department of Health while the private chemists/pharmacies and private doctors were regarded as a different tier of biomedical health. In most cases, the private biomedical health providers were only utilised when participants were not well cared for in the “formal” biomedical health facilities. This, attitude, however, remains unclear as the private biomedical practitioners are known to be more costly but also provide “better” and timely services than the formal primary health facilities regulated by the government. This



debate on the differences between the types of biomedical health practitioners and providers, however, is outside the scope of this study.

### 3.3 Traditional Health Systems

As shown in many studies, the use of traditional healing is common in rural South Africa. Similar to people who have different illnesses such as mental illness, TB and other health conditions as shown in literature (Callan 2005; Kirmayer 2014; Knutsen 2010; Teuton et al. 2007), PLHIV in this study also showed frequent use of TAM. They presented different patterns of plural healthcare use. In using the traditional healing system, the participants displayed varieties of categories and patterns of usage, parallel, concurrent and sequential use, as stated by Nikhil, a 33 year-old male participant who was a traditional healer on ART. He said, when growing up, “*they used to treat us traditionally and also the clinic sometimes*”.

Amongst the participants, there was a strong belief in the role of the ancestors in their daily lives, which includes their health.

*I go to the hut and inform the ancestors that ‘I am not well, can you please get me well and allow me to maybe use pills’. I ask them for the pills to work because sometimes when you are taking pills without telling them, the pills won’t work. If you didn’t inform them they asked themselves that what is this that you are giving them, because you tell them everything you are doing. Even if I have to travel, I tell them and ask them to go with me. When I have headache and want to use snuff, I ask them that if I use this snuff it should work. I use snuff because it won’t affect my treatment it will just drain that pain. Even when you give muthi to a patient you must ask them (the ancestors) for that muthi to work for that person because that person came to consult you because they (her ancestors) make them to come to you and that spirit is the power that they gave you. (Lindiwe)*

Lindiwe stated that she had had a long history of back pains and had been on medication for it, however, she was unable to take any medication without seeking permission and receiving consent from the ancestors. This, she said, was because they are responsible for granting any healing to her or her patients. Thus, seeking their consent before using any medicines allows for the medicine to be efficacious; the absence of such a consent process renders the medicine invalid and does not lead to any health improvement. This is so because as shown in literature

(see, for example, Kale 1995; Moshabela et al. 2016; Naidu 2013; Naidu and Darong 2015a, 2015b, 2015c; Zuma et al. 2016), a key aspect of many African communities, including the amaZulu (the study participants were amaZulu), is the belief in the ancestors and their role in people's daily lives. Hence, as stated by Kale (1995), all daily phenomena, including health, are seen not only from the perspective of nature, but primarily from a supernatural perspective.

Some of the participants may be regarded as 'parallel plural health users' as they made use of the traditional health system in parallel with other health systems for different illnesses. One of the participants in this category was Mkhumbuleni who, when asked if he only started using traditional medicines as an adult, said no,

*... it was something I am used to because you know men if you feel that you are not well, I get something that will help me ... When on the diabetic medication, even the urine is hot, getting the izimbiza helps to open the tubes to go back to their original state. After drinking the izimbiza, you pee and feel that you have been cleaned. There are things that are going out from inside or you have enema and notice that well somethings have gone out not because of body pieces but the waste that was kept there... the izimbiza helps to detox. After the cleaning, well I felt that no I feel fresh. If I was feeling dizzy, maybe not feeling well or tired, it goes away. All of them if you are taking [ART] pills and [pills] for diabetics, you can feel that there is some cleaning that has been done. (Mkhumbuleni)*

He said he uses traditional medicines to boost his sexual life because his diabetes and HIV medication made him tired and weak. The traditional medicines he had most commonly used were sexual enhancement herbs from the traditional healer, not for treating the diabetes or HIV.

*I just take out gall juices. Maybe it could be that which was called... (trying to remember the name of the herbal mixture he uses, he stood up to look for the container). Yes, (picking up a white container with a printed paper label wrapped on it), it is suspension, yes... and I have a runny tummy. It wouldn't be for what I have (HIV), it's for fixing my system in another way (laughing) and feel it that it [his system] is really changing. It [his herb] is really helping. If I can keep on taking only pills sometimes it feels like I am locked in my bones of which I don't know what is causing that. Finding out that even to be horny,*

*to have lust, you find out that it is ay, difficult (laughing). Yes especially the one for the diabetics. They are really killing the feelings for real. So maybe once after two weeks I do the enema with that imbiza. It detoxes me, cleaning the whole of my body. Maybe it could be full of... they call it rough stools. Clean that rough stools and you will feel good saying ooh it's clean. (Mkhumbuleni)*

Being a 61 year-old strong-looking man with a 25 year-old girlfriend, Mkhumbuleni was eager to stay strong, especially in relation to his need to satisfy his girlfriend sexually. Why the emphasis on sexual prowess, one may ask? This needs to be considered as part of the view on gender and gender roles in most traditional African societies. This view is that it is a man's role to ensure he satisfactorily provides for his female partner, including providing maximum sexual pleasure (see, for example, Eagly and Wood 1999; Hood 1986; Thompson and Walker 1989; Wilkie 1993). Therefore, Mkhumbuleni, and possibly other men, as stated by some of the nurses in the study, felt the need to ensure they could satisfy their female partners sexually or they stand the chance of losing them to other men. Mkhumbuleni's girlfriend was a tertiary education student at a technical college in a different district, though her family home was within close proximity to his home. The woman was 36 years younger than Mkhumbuleni. Most of her time, if not at school or with her mother and two daughters, is spent with Mkhumbuleni at his flat. Mkhumbuleni had been on diabetes treatment from 2008, the same day he was tested HIV positive. He lamented how the diabetes treatment had contributed to his low sexual prowess. Although he only started his HIV treatment in 2012, Mkhumbuleni also believed that the ARVs, being "strong medications", have contributed to his low sexual prowess and inability to be fully sexually active.

Literature (see, for example, Bacon et al. 2003; Laumann et al. 2005; Laumann, Paik and Rosen 1999; Verma and Collumbien 2003) has shown that men are more likely to seek help to boost their sexual prowess than they would with any other health condition. The help, however, depends on the health beliefs of the man as well as the social, cultural and economic situation they face. While some men may make use of private doctors and hospitals or government facilities to seek sexual help, others resort to the use of traditional medicines and herbs for detoxing, as they believe that such practices will enable them to regain their sexual prowess. Despite his use of traditional medicines and healing, however, Mkhumbuleni always visited the clinic for his ART, diabetes medication or any other health issue.

According to Burke et al. (2007, 1438), sexual dysfunction is a combination of different aspects of a person which can be affected by diabetes in forms such as low “sexual drive, erectile (dys)function, ejaculatory function, sexual problem assessment and sexual satisfaction”. A strong relationship has been established in literature between diabetes and erectile dysfunction, especially among men (see Bargiota, Dimitropoulos, Tzortzis and Koukoulis 2011; Bhasin et al. 2007; Burke et al. 2007; De Berardis et al. 2007; Rendell et al. 1999; Romeo et al. 2000). This relationship has been recognised since the 10<sup>th</sup> century when Avicenna<sup>22</sup> referred to the “collapse of sexual functions” as a complication in the understanding of diabetes and its effects on sufferers, especially in men (Bargiota et al. 2011; Bhasin et al. 2007). Although sexual dysfunctions are equally experienced by both diabetic men and woman, as stated by Bargiota et al. (2011), more emphasis and studies have focused on diabetic men’s sexual dysfunction. Regardless of the emphasis in research, open discussions and rigorous studies around the sexual dysfunction experienced by diabetics only gained vigour around the 1950s, mainly due to taboos surrounding sexuality and all discussions around it (Bhasin et al. 2007). The numerous studies in this field all show that men as well as women, with diabetes, have more risk of erectile or sexual dysfunction, even at earlier ages, as opposed to the sexual function of non-diabetics of the same age groups. According to Bargiota et al. (2011, 196), such an occurrence “is related to duration of diabetes, poor metabolic control, and the presence of diabetic complications”. Thus, health care providers are able to note sexual dysfunction as a key indicator of the sufferer’s vascular or critical health status. This association between diabetes and sexual dysfunction increases with age, says (Bhasin et al. (2007), who states that this prevalence can be as high as 75% amongst older people.

Aside from the relationship between diabetes and sexual dysfunction, it has also been shown in research that there is a prevalence of sexual dysfunction among about 13% - 74% of HIV infected men, particularly those on HAART (see, Guaraldi et al. 2007, 1059). This belief, thus has led to numerous research being conducted, again, especially among men, to identify the possible link(s) between sexual dysfunction and ART (see Collazos et al. 2002; Crum et al. 2005; Guaraldi et al. 2007; Jones, Klimes and Catalan 1994). These supposed links, however, remain unclear as different studies posit different conclusions. Some studies conclude that ART has a direct effect on sexual functioning among HIV positive men on ART (see, for example

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<sup>22</sup> Avicenna was a Persian Islamic physician and philosopher who lived around 980-1037. Pouyan (2015) saw Avicenna as “the most widely influential Persian contributor to world medicine” and equalled his standing in the Christian and Muslim fraternity to that of Galen (129-299), a famous Greek physician and writer (Pouyan 2015, 165). Pouyan also referred to Avicenna as “the prince of physicians” especially due to the wide influence Avicenna’s Canon of Medicine had within Western universities’ medical course between 1250 and 1600.

Colson et al. 2002; Schrooten et al. 2001). Others, however, express a different view whereby sexual dysfunction cannot be conclusively linked to ART (see, for example, Guaraldi et al. 2007; Lallemand et al. 2007). For example, after using sexual desire, erection, orgasm, intercourse satisfaction and overall satisfaction, as assessment criteria for testing sexual functioning amongst 350 HIV positive men at the University of Modena and Reggio Emilia, Guaraldi et al. (2007) stated that the direct relationship remains inconclusive. They stated that they were able to note the relation between psychological areas of HIV perception, such as self-perceived body changes and mental health, and lipodystrophy to sexual dysfunction. However, the same may not be said of hypogonadism<sup>23</sup> or ART as “androgen deficiency has been the most widely reported cause of sexual dysfunction in HIV infected men” (Guaraldi et al. 2007, 1062). A conclusion about the relatedness of the two health condition could not be reached, as doing so could have required the testing of the effect of each of the pills used, which was not possible in this study. Currently, the different combination for each level of care is used as a single dose for treatment. Therefore, researchers may stand a greater chance of knowing the possible link between the effect of taking ART and sexual dysfunction.

The participant does not only visit the traditional healer to manage his erectile dysfunction, but also for any problem he has, including headaches where he is given herbs such as *umbhemiso* (a powdery herb sniffed to stop headaches). His conviction in the traditional healing system stems from his experience of its effectiveness, both as a child and as an adult, but also in his belief that Western medications are derived from the same components used by the traditional healer. He said, although he maintains the use of his ART and check-ups, the traditional healer is able to suppress the HIV virus: “*to me yes they do*”. Asked how they do so, he said:

*Where do you think the western people used to make pills? I'm telling you that they mix trees and herbs to make western medicine pills. It is the same thing that applies with the traditional healer. He made his muthi by mixing trees or herbs.*

Mkhumbuleni grew up with traditional medicine given to him by his parents. He said “*when we were sick we were taken to eZinyangeni and all those things*”. He expressed confidence in the medicines as he said he experienced a better state of health after using the herbs. His use of traditional medicines and healing was known to his biomedical health providers at the clinic:

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<sup>23</sup> Hypogonadism is a health condition where sex glands, also known as gonads, produce low or no sex hormones. This condition occurs in both males and females. In males, the gonads are the testes while in women they are the ovaries (Martel 2015; Mayo Clinic 2016).

*“they know, I told them [laughing]. I am the one who can feel that no I don’t feel alright now, and then I take my traditional medication... What can they possible say, I am my own man”.*

Some of the participants also made use of traditional healing to treat body pains, shaped by their understanding of the causes of such pains.

*When I was growing up there were obstacles which disturbed me actually. There was a time almost two years when I couldn’t walk – I was like a crippled do you see... actually I had a problem with my ankles and knees do you get it? It was just a thing, a thing but after sometime I got better. (Mqondisi)*

In Mqondisi’s case, his body aches were not due to any natural causes, rather from what he termed *isilwane*. He said:

*... after some time we went for consultation we found out that no there is isilwane (isilwane is a form of spell made on a person to hinder them from succeeding in anything they do). They said I have the isilwane ooh, so now this isilwane as I’m still at school what must I do, quit school and deal with this isilwane?*

Visibly irritated by thoughts of what his paternal family did to his mother, his siblings and himself, Mqondisi stated:

*I don’t even want to talk, actually I’m not a talkative person. Most of the time I point out that I don’t like this and that, I don’t even utter the words I just keep quiet with it. Nobody was left at home because even my sister never goes there. Till now they don’t show – they just laugh and show teeth and you won’t really see what is on their mind. So you can go to them seeing them laughing and you think they are good people but they are pretending.*

Mqondisi asserted that not only was he and his mother affected by the “bewitchment” from his paternal family – his father was also “bewitched” but did nothing about it. He said: *“They also did to him even though he kept quiet about it. So I don’t think he didn’t know about mine, it’s just that he didn’t raise it”.* Due to the spells Mqondisi believes have been cast on him and his immediate family by his paternal family, he is unable to get a job or maintain a relationship with his female partners. He constantly visits the traditional healers to conduct rituals to unbind him from these spells.

Another category of participants in the study were those who use the traditional healing system sequentially. This category involved those who were users of traditional medicine but also use biomedicine and are open to continual use of the traditional healing system if they experience certain illnesses that they consider culturally bound. There were also those who were dominant users of traditional medicines but were intending to return to their use of biomedicine after conducting rituals with their traditional healers at the time of the study. This category also involved participants who were users of traditional medicine in combination with biomedicine and faith healing.

### **3.3.1 Treating *umkwebhelo* with Traditional Medicines**

Sifiso, who had previously made use of traditional medicines and healing, but was a sole user of biomedicine as at the time of the study, expressed his inclination towards using traditional medicine. This is due to his knowledge and belief that certain illnesses are culture-bound. These are health conditions that occur in specific contexts and are only explainable within those contexts and not within a wider understanding of health and illness (Griffith 2014). Thus, Sifiso stated: “no I don’t do that [use traditional medicines] currently. I don’t go for that because they [nurses] said it clear at the clinic. They told us not to mix pills and not to use things that will make us throw up” (referring to traditional mixtures that users take to make them nauseous and vomit).

*I used to threw up and enema. I used water only. They told us at the clinic not to do the enema then I stopped. I thought of doing the enema then you phoned and I decided not to go ahead with it. Yes you phoned then I stopped doing the enema. I felt that my stomach was upset then I thought of enema. (Sifiso)*

Sifiso has been informed by the clinic that he should not use enemas or medication that will induce vomiting as this would affect his ART routine and he could vomit the ARVs before they are absorbed into his system. The clinic nurses and counsellors “told us at the clinic [during initiation to ART] not to do the enema then I stopped”. However, during our third visit to Sifiso in his home, he expressed openness to using the traditional healing system. He felt that his mother ought to have been given *imbiza* (a traditional herbal mixture) when she suffered from *umkwebelo*.

*It is an illness that the feet become swollen, swollen head and stomach, just like that. Eventually sores develop then they would say its diabetes. Yes it has*

*diabetic's symptoms... The umkwebhelo makes the feet to peel off as if they have impehlwa [infection which develops under the feet]. ... but if you can quickly get traditional herbs and use them it quickly heals, it is one thing... You must get izimbiza then the last option is to go to the hospital, maybe getting a person who knows izimbiza first then you go to the hospital later. (Sifiso)*

He said people get the condition for different reasons, in his mother's case; it was because she was being called to be a *sangoma*. He said when people notice the condition:

*... that is when they say they must go for isangoma training; others say they should go to the hospital and they cut the foot... They develop here on feet. It affects one leg. They cut it bit by bit until it comes to another leg and go straight up. They will cut it again. My uncle had this illness. He didn't survive. They cut him and he used the wheelchair, both legs. My mother went to someone who said she had the same illness as my uncle. They [doctors] didn't cut off my mother's foot but she was due to be cut off – well the family refused and they fetch her and she was brought home... She came back and stayed here then she went back to the isangoma's house saying she was going to the isangoma dance but it was all the same. She ended up dead. My other sister who is also late said she must fetch her but she was about to die. They got there when she was already gone [he kept quiet briefly before he continued speaking]. They thought of fetching her in that afternoon and they found out she was already gone. She died at isangoma's house. It was only umkwebhelo. (Sifiso)*

Asked why he felt a person needs to get traditional help first and what makes him sure that this is best, he recalled a person who used this approach first rather than going to hospital like his mother and uncle had.

*I say this because one [of my neighbours] had umkwebhelo, [he] took izimbiza and felt better. Then he went to the hospital and came back without his foot being cut off [as done to those who go to the hospital first]. He then got sick with something related to asthma... Yes he thought he had it [diabetes] as they said at the clinic that it was diabetics but it was just umkwebhelo. So he took izimbiza and he felt better... Ooh I have seen that many people just die. Once they go to the hospital and they cut them. Even the one who was training my*



*mother was cut off eventually. She suffered from it. Her leg was swollen, the aunt didn't survive it, and she died of umkwebhelo. There is no one that I know who suffered from umkwebhelo, used izimbiza and whose foot was cut off. It is better if you are taking izimbiza and go to the hospital later. (Sifiso)*

In this case while Sifiso does not dismiss the use of the biomedical health facilities in determining or treating the condition, he firmly believed that using traditional medicine first helps people to survive the condition; many people seem to die if they use biomedical treatment first. Although he agreed that a certain condition might have the same symptoms as diabetes and can even be regarded as the same thing, it does not necessarily have the same cause nor need the same treatment as diabetes. While diabetes may be treated biomedically as it is caused by biomedical factors, *umkwebhelo* should and can only be treated traditionally as it has its causes rooted within the traditional health frame, he said. His belief and use of the health system, is thus a sequential approach where he chooses what health system to use, depending on the condition or the stage of the condition.

### **3.3.2 Cleansing “Dirty Blood” with Traditional Medicines**

Mqondisi was another participant who had a sequential approach to plural health care seeking but was a predominant user of traditional medicines at the time of the study. In his bid to regain his health after experiencing prolonged coughing, he had visited the clinic for a check-up to find that he had TB and HIV. Before going to the clinic, however, he had consulted his traditional healer for a variety of reasons. The first was when he had shingles and on three occasions when he had *isilwane* and “dirty blood”. He was familiar with the traditional health-seeking territory. Hence, when he was told by the nurse at the clinic that his blood was “dirty” after his HIV test, he immediately decided that he needed to visit his traditional healer who would be able to clean his blood. This was because he believed that:

*If the blood is dirty there is no illness that you will not suffer. If you have illness in your body you won't gain weight. Being ill won't make you fat, it really won't happen. Instead of gaining weight you will lose weight and then people will say this one is dying and wonder what is killing him ... ooh this one is dying of AIDS he just doesn't want to admit it.*

Mqondisi appeared physically strong and healthy, which he needed to be, as a builder. He said he was strong as he was being cleansed from the dirty blood, thus revitalising himself. He stated that after four further cleansing sessions, he would go back to the clinic to check how clean his

blood had become. Mqondisi's understanding of HIV/AIDS, as shown by Golooba-Mutebi and Tollman (2007b) and Naidu and Darong (2015a), stems from the belief that a person becomes ill, no matter what the illness is, because there are unwanted elements in the person's life, which could have been caused by others in the community, but also by the ancestors. If the illness is in direct connection to one's blood, the blood is said to be unclean, and needs to be cleansed. Mqondisi's use of traditional healing is sequential and he was willing to use biomedicine, but this did not stop him from using his traditional medicines. He said:

*I won't stop ever, even now I have it. I have it right now, if it's finished I get another one. I should have told her [the healer] but I realised that its helping me sometimes because I used to have sores that came up yet this herbal mixture kills it inside, you see? Now I realised that if I stop to use herbal, what if the sores come up again then I should start afresh paying the traditional healer again? No, I must use it because it's not giving me any problem, any running stomach or anything.*

Because Mqondisi had suffered no ill effects from his use of traditional healing (in fact, he had experienced only positive outcomes), he believed in its effectiveness and continued to use it. He also continued to use biomedicine at the same time. This shows Mqondisi's ability to fight against the 'violence' of the different health systems and to express his agency through making decisions as to what he felt worked best.

### **3.3.3 Treating TB with Traditional Medicines**

The effect of HIV on a carrier's immune system makes them continually susceptible to tuberculosis (TB) (see, for example, Charalambous et al. 2008; Golub et al. 2008; Lawn and Churchyard 2009; Lawn et al. 2006a, 2006b; Nahid et al. 2007). In making use of multiple health systems, some of the PLHIV in the study sought help in treating TB using traditional healing as they had had recurring experiences of TB. Mqondisi, aside from visiting the hospital when he had TB, also visited a traditional healer when he repeatedly experienced TB in hope of understanding why this was happening and in an attempt to treat it.

*She [the traditional healer] gave me the muthi to kill these things [the illnesses he had] inside me [coughing] because what she gives me is for cooling down. You see when she gives me this for cooling, when it suppresses then I will be able to take it out. The medication is for drinking and licking. It is dry, it is like mealy meals (maize powder)... she works on dirty [conditions] like this.*

*She works with these that I was consulting for. She saw it that I have things like that. She gave me her things [herbs] for all that she saw; those are the things she is working on. I wanted her to disassemble the problems and she did so. I started seeing her in January this year [2016] and it's August now... I am good really. Maybe the doctor will tell anything he likes but I am fine. I don't have anything, anything. I am feeling better than the previous time. (Mqondisi)*

This 41 year-old participant, Mqondisi, who lived in his maternal grandparents' house due to family issues that he considered to be related to "bewitchment", expressed absolute confidence in the traditional healer he visited for the numerous health conditions, he had, including TB. He had also had recurring TB, about three times. He asserted that the medication given to him by the healers helped him in regaining his health and that even if a doctor told him otherwise; he would not believe the doctor. This, he claimed, is because he feels completely healthy as he has been treated by the traditional healer and cannot be lured into believing that anything else is wrong with him. This attempt to use traditional healing for the treatment of TB may be linked to what can be termed a traditional understanding of tuberculosis as shown by some of the participants, but also the expression of creativity in deciding how new possible health pathways can be created or recreated.

Charalambous et al. (2008), in their study of factors contributing to the recurrence of TB, especially around South African gold mines, noted that recurrence of TB, often after cure, is highly prevalent in locations with a high prevalence of TB and HIV. Beyond the role played by specific locations in contributing to recurrence of TB amongst PLHIV, "HIV infection... and drug resistance" were identified in the study as some of the identified risk factors for recurrence of TB (Charalambous et al. 2008, 942). Thus, recurrence amongst the participants in this study can be linked to either an endogenous factor such as drug resistance, which often leads to a relapse, or exogenous factors such as re-infection from already infected persons. Speaking about what could have led to him experiencing TB multiple times, Nqondisi said:

*[Coughing] then after that [experiencing TB the third time]... [Coughing] I went in January, I went to St Lucia. There is a person who is helping me there. He told me that it's not right, it's not right. He said, "you see even now you are dead, yes you are dead". Hey [exclaiming]! He gave me fright you know. What? Dead? And he said "the way you are bewitched... the way you are bewitched, ey, it's hard but he will try". He said I've got so many things in my*

*blood like idliso [poisoning], but he will try. He said I've got idliso from birth, "they bewitch you with every madness like the grave soil", he said. Do you think you can live after that [asking the interviewer], eating those madness?<sup>24</sup> I don't know the wools that came out you see. (Mqondisi)*

This belief in what could have caused him TB was responsible for his choice of treatment (traditional healing). This is a psychosocial view of the illness, which means it was contracted “traditionally”. Psychosocial health conditions will be those conditions that participants believed were either inflicted on them by other members of their community and family or by the ancestors. The reasons for the inflictions, however, as shown in different studies and also seen from the participants in this study, vary from person to person. The effects of the infliction were also either physical or spiritual, irrespective of the causal factor of the health condition. In both aspects however, the conditions are strongly believed to be rooted within the psychosocial realm or traditional practice. Their means of treatment are also rooted within the realm of traditional health practice and healing. Mqondisi, who had repeatedly suffered from tuberculosis (TB), for example, had dropped out of care from the clinics at the time of our interviews with him in order to seek help from a traditional healer. Narrating his experience of TB for a third time, he told us how he sought help from a traditional healer who told him what was happening to him was “not normal” (i.e. he should not have had any recurrence of TB). Mqondisi said he fully believed his healer because he grew up seeing people being bewitched and after seeing a traditional health practitioner, they became well and healthy.

While some of the participants used different health systems alternatively for the same or different conditions and some made use of a parallel approach whereby they used different health systems at the same time for different illnesses, others made use of different health systems concurrently for the same health conditions. The first experience of concurrent treatment by the participants was the treatment of HIV/AIDS symptoms at biomedical facilities as well as using other health approaches.

*When I am using traditional stuff, the clinic is unable to identify the blood status.*

*While I cannot say the traditional muthi has an influence in curing HIV virus, but hmm, I can say it did help in other illnesses in the blood and as I have been*

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<sup>24</sup> Towards the end of the interview, the participant explained what he meant by the “madness”. He was born into a turbulent family which was marred with in-fighting, especially using traditional and spiritual powers and means. His father’s family, he said, hated him and so bewitched him. Hence, he left his father’s home to live with his maternal grandmother to avoid being ravaged by the continuous spiritual battles that took place in the family.

*infected, it really helps like to treat piles. I used to suffer from the piles as I am HIV positive and they said sometimes it's an opportunistic disease. When I suffer from it I don't go to the clinic, I just get the imbiza then it's finished. But if I used the clinic, it doesn't get treated. Although the clinic has things to treat it, but if you are lucky they cure your piles. It depends on what kind of piles. There are piles with problems of infection like it's just something that will pass, that one is easy because the clinic can cure it. The one that I have is very difficult because it can't get cured that easily. I have to get imbiza so that I will be able to cure it. If it starts again, I feel the pain on the anus then it grows the flesh, then I use izimbiza then it stops. The flesh goes back, but it doesn't mean that it's gone permanently, it just get back after some time. (Nikhil)*

The treatment of HIV symptoms with traditional medicines has been widely researched, especially in Africa and within the South African context (Babb et al. 2007; Kisangau et al. 2007; Moshabela et al. 2011; Peltzer et al. 2008). In some contexts, such plural health seeking has been regarded as an attempt to treat HIV/AIDS and a barrier to enrolling in ART (see, for example, Lamorde et al. 2010; Moshabela et al. 2011; Weiser et al. 2003). In some cases, however, individuals engaged in such health-seeking as a way of treating the symptoms they were experiencing without any realisation that being HIV positive can lead to the experienced symptoms. Regardless of the motivation, some of the participants in this study, such as Nikhil and some of the biomedical health providers, reported how the use of some traditional medicines can lead to suppressed viral load. The nurses, however, view this suppression as simply a smokescreen which affects accessing the actual viral load of the patients.

Although some of the traditional healers in the community had attended some training on HIV/AIDS, organised by the African Medical and Research Foundation (AMREF), Nikhil said he was never part of such training. He said he had not had much formal learning about the illness aside from what he learned from the clinic. While he had learned about HIV/AIDS from the clinic, his view on how to handle people living with HIV around him or who consult him, remains inconsistent with what the clinic and other biomedical institutions often advise. He said he is able to see the symptoms of HIV in a person, such as loss of weight, and he always advises such a person to go to the clinic first before they visit him. This approach, however, may pose difficulties to how Nikhil identifies PLHIV, especially in an era where ART is widely taken and PLHIV have shown to be able to live very healthy lives and do not present some of the symptoms previously linked to HIV, especially weight loss. When he is to use sharp objects

on any of his patients, however, he uses latex gloves to protect himself and the patient from getting infected. Although he remains uncertain if HIV can be cured by traditional medicine, he believes that the *muthi* he uses can suppress one's viral load as well as treat some opportunistic infections, such as piles.

Another health condition which a participant in the study sought treatment from different health providers for concurrently was kidney failure. The participant presented the concurrent use of different health systems, biomedical, traditional, and spiritual health systems in treating his swollen stomach.

*[Laughing] ... eeh now I don't remember clearly maybe sometimes they call them with names of inyanga like this thing, there is this herb, the ilabatheka This thing is something I wouldn't know how it is, but if I remember clearly it is a bulb. Yes it is a bulb. It is found down in this thing... in the soil there in Hluhluwe. You take it and peel, peel and peel carefully taking out this bulb then chop and chop it. Because I used it while I was sick I had used that for the ubunyanga, because even granny said I should use it. She said I must use it. Well I used that thing, you take water put them there, you boil it in water. When it is cool you take it out, pour the mixture in a container and drink.*  
(Cothoza)

Asked if the traditional healer knew that he was also using herbs from other healers and the holy water and oil from the Nazareth Prophet, he said he knew because they (his aunt) had explained to him. Multiple health providers contributed in Cothoza's health journey. This contribution often took place concurrently with Cothoza constantly hoping for help from any of the health providers he visited.

Cothoza expressed how he had struggled deeply with a variety of illnesses and a complex health-seeking process. His experience of kidney failure was one of the experiences that led him to be a plural health user. Despite some of the illnesses researched and treated within the biomedical sphere, treatment, however, seemed best using multiple health systems. Chronic kidney disease has been defined as "either kidney damage or decreased kidney function (decreased GFR) for three or more months (level A recommendation)" (Levey et al. 2003, 138). Levey et al. (2003) stated that, regardless of cause, the major effects of kidney disease are usually kidney failure, "decreased kidney function and cardiovascular disease (CVD)" (2003, 137). Acute kidney injury and chronic kidney disease have been identified as some of the key

complications of HIV infection and have more dangerous effects on ART users as they get older (see, for example, Flandre et al. 2011; Röling et al. 2006). This prevalence of reduced kidney function amongst PLHIV has been reported to be between 4% - 17% (Cheung et al. 2007; Mocroft et al. 2007). Cheung et al. (2007) specifically associated *indinavir*, and ART pill, to a decline in renal function among ART users. Another ART medicine, *atazanavir*, has also been associated with poor renal function by Brewster and Perazella (2004). Similar concerns about a harmful effect of an ART drug, *ritonavir* were voiced by Danner et al. (1997) and Duong et al. (1996) who claimed that the intake of *ritonavir* was risky, especially by PLHIV who asserted that a continuous use of the medication causes pressure on the kidneys and their capabilities. Similar assertions have been made about *tenofovir* (Mitra et al. 2014) and *didanosine* (Izzedine et al. 2003).

For instance, Mitra et al. (2014, 28) stated that about 20 – 30% of *tenofovir*, being a “potent component of first and second line anti-retroviral drug regimens... is excreted unchanged in the urine via active secretion by the proximal tubular cells”.<sup>25</sup> This process causes damage to the tubular cells, the consequence of which, according to Mitra et al. (2014: 29) “leads to variety of nephrotoxic features, which includes Fanconi syndrome, chronic renal failure, acute on chronic renal failure, etcetera”. As Cothoza only started his ART programme in 2015, despite being diagnosed of HIV from 2009 and having undergone TB treatment from 2001, other causal factors besides his ARVs could have been responsible for his kidney disease, despite the relation between the two shown in research. Cothoza was a high alcohol consumer during his prime years, especially when he worked at the mines in Johannesburg for 10 years. Admitting to his doctor that he was a high alcohol consumer shows that he understood and could see the potential damage the alcohol and the exposure to the dusty air he had in the mines would have caused. Despite this understanding of how his health conditions would have been caused, he still sought treatment from multiple health systems to treat the health condition, including a traditional healer.

### 3.4 Use of Spiritual Healing

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<sup>25</sup> According to Pathway Medicine, the proximal tubule is “the major resorptive segment of the nephron and accounts for resorption of nearly two-thirds of all filtered water, sodium, and, and chloride. In addition, the proximal tubule is the segment where the majority of critical organic solutes such as glucose and amino acids are resorbed. Finally, this segment also plays an important role in acid-base balance as it is involved in bicarbonate resorption and secretion of organic acids” (Pathway Medicine 2017). Hence, when tenofovir is ingested, the Organic Anion Transporter receptor which is based at the basolateral surface of the tubular cells absorbs it. The drug, however, is then excreted into the tubular lumen through the multi-drug resistant proteins found in the proximal tubular (Mitra et al. 2014: 28). The continuous repetition of this action through a continual ingestion of *tenofovir* damages the proximal tubular, an action that leads to a slow, poor or lack of reabsorption in the kidneys.

In South Africa there are a number of religious healers who have great command over their followers. The extent of the influence of the preachers on their followers and the faith shown by the followers is often seen in the followers' willingness to obey and carry out whatever actions are commanded by the preachers. This is so even when such actions are known to be biologically detrimental to the health of humans (BBC News 2016; Jamal 2017; The Citizen 2017a; The Citizen 2017b; Vilakazi 2016). It is with such faith and beliefs that plural health users often seek help from religious healers for different health or socio-economic conditions. Nonetheless, believers in religious healing, regardless of their belief base, often depend on a connection with an unseen supernatural and powerful being whose invocation is believed to have an ability to heal. Seeking spiritual help is one of the approaches commonly used in the country and certainly by some of the participants in the study. Although amongst the study participants, spiritual healing is not necessarily the popular Pentecostal healing process, they hold and give reverence to a higher being, whom they see as playing an active role in their lives and has an ability to heal them of all ills.

One of the participants sought treatment for his kidney disease from a faith healer, whom he said, was able to heal him. Cothoza had visited all three major health systems in the community. After moving between the hospital and private doctors and different traditional healers, he then met with the spiritual healer of the Shembe Nazareth church. He said:

*I went to the Prophet of the Nazareth and he said, "the God of Shembe will help you, you will live, [and] may God bless you. He said that to me, "use the oil and this water, respect the Sabbath". Eeh since then I committed myself in using this water and applying this oil onto this stomach, and drinking holy water. Sometimes maybe I put them here at the back (enema) sometimes applying the oil, most of the time, and again kept on praying. I was using both of them then [faith healing and biomedicine for TB treatment]. I couldn't stop it [TB treatment]. Before that time I was mixing with muthi, and then I had stopped using the muthi. I had completed the muthi treatment without any positive result. (Cothoza)*

Although Cothoza had hoped to receive healing from the Prophet after he first visited him, this did not happen immediately. He felt that his use of *muthi* while also using the Prophet's holy water and oil might have interfered with the work of the holy water and oil. Hence, he stopped



using the traditional medicine. Although Cothoza's illness led to physical symptoms of a swollen stomach, he believed that there was some form of spiritual influence to his illness as doctors and even traditional healers (whom he trusted) were unable to assist him. Turning to a religious healer was an act of health-seeking in a complex system where he feels disappointed by the numerous health systems he had sought help from. Thus, with further contact with the religious group, he became a devoted member of the religion with a strong belief in God and how God is able to handle what people struggle to take care of. His total surrender to the powers of God through the holy water and oil are a display of the trust he had. Through his prayers and application of the oil from the prophet and drinking the holy water, Cothoza finally received what he regarded as, his healing from the God of Shembe. Although the "healing" took place after being treated in the hospital for about five years for kidney failure, he was of the belief that it was the God of Shembe that healed him and not his operation. Thus, he felt fully indebted to Shembe and the Nazareth religion.

It has been shown (see Gabasiane 2014; Niezen 1997; Rozario 2009) that when a people have a strong belief in a supernatural being in the form of God, they are likely to turn to that being when in times of trouble. Gabasiane (2014, 15), for example, stated that as a child, after experiencing what he regarded as a saving miracle from jealous neighbours who wanted to poison their family, his father who was a pastor said to them that the only way they "could be protected from the threats of life was to pray and trust in God". On the day Cothoza was finally healed from the swollen stomach after traveling with a 4am bus to the hospital, he said his prayers and had his oil and holy water. He asserted:

*[While about to be drained of the liquid in his stomach] I was praying that 'Lord everything that will be done to this body please may it not be the doctor's hands but your hands God and let everything be a success and I get to live'. On that day I was separated from this water as you can see my stomach is like this, it's plain like everybody's. (Cothoza)*

This combination of prayers and other anointed materials is common in the seeking of religious healing. For instance, in a study conducted by Pawluch, Cain and Gillett (2000), prayers were regarded by the participants in the study as contributing effectively to their healing and well-being. This act of prayer, however, is held in high esteem amongst different belief systems, not only believers in religious healing. Although the swollen stomach had been healed as at the time of the study, Cothoza still experienced momentary pains in his back, which he said might be linked to the liver problems he had. He stated that "it is not healed, because I think there is

*a wound inside*". This however, he did not report to his Prophet. He said: *I would be lying there; I didn't report that there is a wound here. I still drink [the holy] water. I apply the [holy] oil, I just apply them.*

Aside from his experience with the kidney failure, Cothoza also had a belief that he was at some point being tormented by evil spirits. Hence, he made use of holy water from the prophet to sprinkle around his yard. He expressed a deep belief in the ability of his holy water to protect him from characters he termed "evil spirits". These characters, he said, tend to want to disturb people at night and torment them, especially given that he lives alone. He said he needed to ensure that he was well protected against such spirits and whatever plans they may have for him.

*Ooh you do know people that sometimes, people send other things what, what, and owls and other things. Do you see things like that and others evil spirits, yes? That just confused me. It really confused me. Well, I would say there are evil spirits, I was just confused, I didn't know. I asked myself 'where did that come from?' (Cothoza)*

Although at the time of our interactions with him, Cothoza had stopped using traditional medicines or healing, he still had a belief that there are people who are able to interfere with others through evil means. He said such people come to a person as evil spirits to cast spells on a person or harm them. They come to a person at night, he said, in form of animals, such as an owl. He stated that, if not taken care of, such spirits can end up tormenting a person, worse if such a person lives alone as there would be no-one to know what was happening. Nonetheless, Cothoza lived alone; he said he was comfortable with this. He had been living alone for more than a decade, since he moved out of his uncle's home. He said he moved out as he did not feel comfortable being a "burden" to his uncle's wife. He wanted to take care of himself; hence, he moved to his one room apartment, made of mud and pieces of stones, which was about 500 metres from his uncle's home. Cothoza seemed to enjoy his quiet and alone time, however, he was always happy to sit and chat with us and we became accustomed to each other.

Another participant, Nikhil, also engaged in the use of spiritual healing. Unlike Cothoza who used the healing approach for treatment, Nikhil only used it occasionally to "clean" himself.

*I only use the spiritual things if I want to clean myself. Like [iziwasho], it's the holy water with the lucky stone bought from the pharmacy. I used to buy them*

*from the pharmacy in town then I came back and mix it. Yes I do go to church. There at Zion because they also do holy water but the one with prayer not the one with so many things. I don't have a problem using all these systems. No problem really. (Nikhil)*

Although he is a traditional healer, Nikhil uses holy water when he wants to get a job or to clean himself of “bad luck” or if he is ill. He uses holy water to steam himself, for bathing, and detoxing (“throwing up”). He feels he has bad luck when he fails to get a job or is harassed by other people without any reason. His last use of the holy water was the week prior to our visit. He told us he sometimes makes the holy water himself because he wants to see if he can do this on his own. For some health conditions or illnesses regarded as spiritual, participants resort to “spiritual intervention” (Gabasiane 2014; Niezen 1997; Rozario 2009). There are other situations where religious healing is used concurrently with biomedicine, a combination also understood as medical pluralism. As Rozario (2009), after conducting a study in Bangladesh, stated “although *upri* (spiritual) problems can generally be treated only by *imams* (spiritual head) or other spiritual practitioners, and medical problems by doctors, in practice there is no sharp dividing line between these, and both kinds of treatment may be pursued for the same disorder” (78). Rozario (2009) went on to explain that this “side-by-side” seeking of healing in this Bangladesh community is the same in other South Asian communities. Concurrent use of spiritual healing, traditional healing and biomedicine is also found in many African communities. Gabasiane (2014), for example, showed how the *baTswana* engage in plural healthcare by integrating biomedicine into their traditional healing system as well as spiritual healing system, which had existed prior to the advent of biomedicine in the community. The same view was evident in Rozario’s (2009) study: “there was no real conflict between religious forms of healing and medical (*daktari*) treatment. That is, there is no sharp dividing line between *daktari* and *upri* (spiritual) problems, and families will use a combination of ways of understanding and attempting to remedy their children’s condition” (79).

### 3.5 Complexity of a Plural Health User's Health Journey

From the discussions above, it is clear that there is considerable complexity in healthcare options and use in many contexts around the world. This is the case for this study too. The diagram below summarises a research participant's, Cothoza, health care journey over the period 2001 to 2015. Green is used for traditional healthcare, red for biomedical and yellow for spiritual consultations

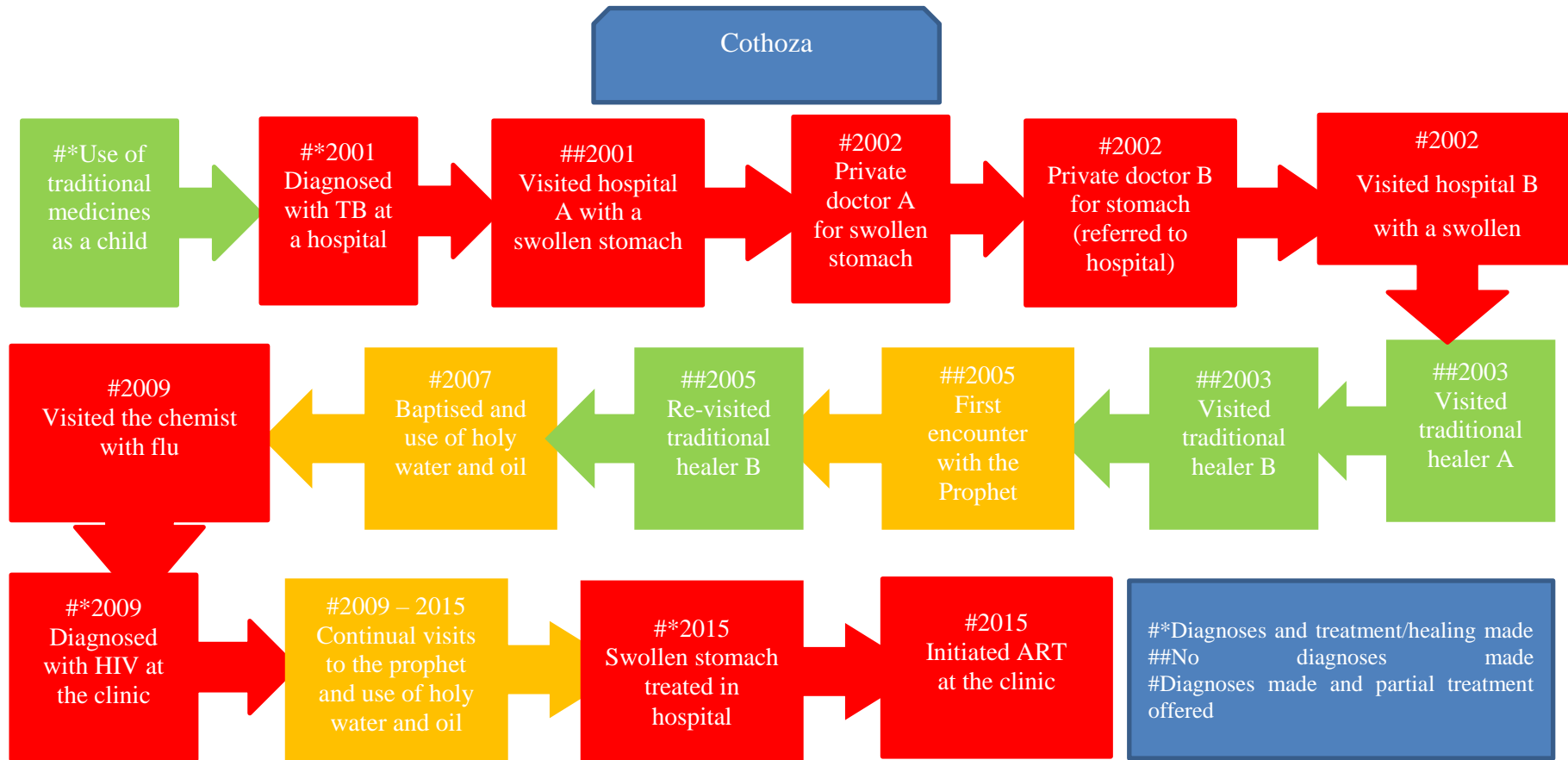


Figure 3.1: Complexity of a plural health user's health journey (diagram adapted from Moshabela et al. 2011)

### **3.6 Conclusion**

With the multiple health options available to the participants of the study, their health world is often riddled with choice-making between different health approaches. These choices were mainly shaped by the health conditions experienced and the participant's health view. While the combination of health approaches did not appear to have become toxic, the use of the different approaches contributed to the conflict they often had with the biomedical health care providers. Their movements between the different health systems were mainly based on the belief that specific situations received better care in particular health systems. In other cases, participants visited multiple health systems with the same conditions, concurrently, sequentially or in parallel. These patterns of seeking health were to a large extent an expression of the participants' agency in carving or recreating their desired health-seeking routes as opposed to the generally expected routes, especially for PLHIV, which is the exclusive use of biomedicine.

The lack of a standard procedure for plural health-seeking, however, has been reported and shown to have led many people into two major dangers. One is in relation to the concurrent use of different medicines where biological effects of the medicines are not clearly known, and combined usage could lead to toxicity. This can lead to drug resistance, or even death, especially amongst PLHIV (see Moshabela et al. 2011, Moshabela et al. 2012; Moshabela et al. 2016; Summerton 2006). The second major danger lies in users falling into the trap of using dubious health practitioners with little knowledge of the medicines or healing process and for financial and other benefits only, unknown to the user (Moshabela et al. 2016). In both cases, users can suffer from crucial financial and health damages (Moshabela et al. 2016; Moshabela et al. 2012; Nxumalo et al. 2011). This chapter has presented a broad picture of the different health approaches used by the participants in the study and described their motivations for using the different health approaches. Behind this outer picture, however, lie complexities that shape the health-decision making of the participants. Despite the complexities, however, due to multiple factors such as cultural beliefs, religious beliefs and health knowledge, the participants were able to make use of the available health systems in the community when they needed them.

## **CHAPTER FOUR**

### **Perceptions and Experiences of Complexities, Dilemmas and Tensions in Plural Health Use**

#### **4.1 Introduction**

The plural health world is riddled with complexities that contribute to plural health users' patterns of seeking healthcare. Literature reveals that factors such as poor access to healthcare services, poor health education, fear of stigma, denial of one's HIV status, avoiding physical and psychological strain or chronic illnesses as well as a high cost of healthcare to be the primary motives for switching between different health approaches (Moshabela et al. 2011; Muela et al. 2002; Nyamongo 2012; Ryan 1998). Movement between different health systems was very evident in the current study; motivations for switching, however, were often multifaceted, in some cases, doubling up. The role of multifaceted factors in the health-seeking patterns of plural health users has not often been given attention in literature, especially how such factors contribute in shaping a plural health user's decision on when to switch from one health approach to another and which approach to switch to. Between the steps of health-seeking taken by the participants are experiences of complexities, tensions and dilemmas regarding decisions on which health system to use. These complexities and difficulties in making a "good health decision" are linked to the illness suffered, the health approaches visited, the user's worldviews (cultural, social and religious), external contextual circumstances beyond their control such as states of health systems or the knowledge base of health providers, as well as their socio-economic circumstances.

While health seekers may be the primary agents to determine what health approach they use, in promoting healthy lifestyles and health-seeking in a community, there are other role players and factors involved in this health-seeking determination. Such role players include the individual seeking health or needing a healthy lifestyle, the community, but also the environment (Mcleroy et al. 1988). The health providers of the available systems also play a critical role. Hence, the views of the various health providers about their role in the healing process of patients in the community contributed to the complexities faced by the patients. This role was either their inability to treat some health conditions presented to them or their attitudes and views towards other health systems. The socio-economic situations of the participants also played a role in contributing to the complexities they faced in seeking health. This chapter

looks at the complexities, dilemmas and tensions experienced by the participants in this study in their health-seeking journeys.

#### **4.2 Complexities due to some Health Systems' or Providers' "Inability" to Treat Certain Health Conditions**

While moving from one health approach to the other, the inability of health systems or providers to deal with some of the illnesses presented by the participants played a critical role in the participants' health use and health choices. This perceived inability to receive appropriate diagnoses and treatment from a health system is often received with disappointment as users feel that their needs are not met. This often leads to desperation, especially when a user wishes to have the fastest treatment possible. Failures to either appropriately diagnose or treat some illnesses were experienced within both the traditional and biomedical approach to health by the study participants.

Some illnesses were reported by participants in the study to have been either misdiagnosed or not treated by the hospital. These experiences, said some of such patients, proved to them that biomedicine does not and cannot have full knowledge of all illnesses or the required skills and treatments for all illnesses. The first issue noted about biomedicine was its lack of knowledge around symptoms related to one's calling to be a traditional healer. Such an inability was mainly due to the nature of biomedicine, which is built on cognitive evidence, whereas the traditional approach to healing does not always rely on cognitive evidence as it holds that ill-health conditions can be caused by non-cognitive factors, such as spiritual interferences. This difference thus limits the extent to which the biomedical health practitioners could go when faced with the treatment of patients whose health conditions might be best understood and treated within the traditional healing system. This inability was in some cases recognised and admitted by the biomedical health practitioners, and in some cases, by the participants. In the case of one of the study participants, these symptoms were misdiagnosed as symptoms of meningitis.

*My husband was very shocked at first when I was suffering from ancestral spirit, when I looked sideways listen to the voice that I was hearing, he thought it was witchcraft. He took me to a healer and the healer said "no she is not sick but she has a calling, only" and he will say no the healer failed to see the illness then he will take me to the clinic. But before I get inside the clinic, everything that I was feeling will disappear. At the clinic I won't even get a*

*drip because the tiredness that I was feeling will vanish, I will just tell them at the clinic what I was having, that my body is getting tired. This thing doesn't want me to go to the clinic. Maybe I will get those pills for pains and come back home, it continues there. (Nolwazi)*

Due to the difference in healing approach between biomedicine and traditional medicine, certain symptoms are sometimes linked to biomedical health conditions whereas they are manifestations of traditional conditions which can only be treated traditionally. In the case of Nolwazi, the pains and tiredness she often felt were directly related to her calling to become a traditional healer. These signs, she said, were prompts from the ancestors for her to seek a trainer who would introduce her to the practice of traditional healing. Until a person called to be a healer “answers” this call, they are likely to have to face unnatural circumstances, even when such circumstances appear natural. As Truter (2007, 57) stated, “...training to become a *sangoma* is not a personal choice but is a calling bestowed by ancestors”. Despite the attempt by the clinic to diagnose meningitis through a lumbar puncture, they were unable to diagnose her; neither could the hospital detect what was wrong with the participant. Such a “failure”, especially from a health approach that most community members were encouraged to use as opposed to using traditional healing or other sources of healing, can potentially lead to distrust in the system and its effectiveness. This is more so when such health conditions are treated using other health approaches. Instances (see, for example, Bourke and Shields 2009; Hoffmann et al. 2009) have been shown where meningitis has been misdiagnosed for other illnesses such as Alzheimer’s disease. While this may be primarily due to difficulty in differentiating between viral illness and bacterial infections, as noted by Bourke and Shields (2009), this can also be because the symptoms are due to conditions that the biomedical health facility is unable to detect. Such cases are often related to health conditions that are either culturally bound or directly related to traditional or spiritual practices, as stated by Naidu and Darong (2015a) and Truter (2007).

In another case, the primary biomedical health practitioners visited by one of the study participants were unable to detect that he had a liver disease when he visited the facilities with a swollen stomach. While experiencing liver illness, Cothoza sought help from different providers, some of whom were unable to diagnose the right condition, hence were unable to treat him. Cothoza said:

*When I had this water [in my stomach], the private doctor checked me and said “no this thing that produces this water is your liver”. But in the hospital,*



*when I asked them, they didn't say it was this thing. The [private] doctor also said he will make me a referral letter to go to the hospital yes but he didn't make me that referral letter because he treated me with his medication and it felt better. (Cothoza)*

When Cothoza had a swollen stomach it was an “unknown” illness with worrying symptoms. Visiting the hospital did little to ease this worry as the hospital, which he expected to be the primary health provider in the community, was unable to diagnose or explain why he had a swollen stomach. The diagnosis was only made by his private doctor and healing eventually came from a faith healer. Although private doctors are part of the biomedical system and use the same guidelines as practitioners in primary health care, they often operate outside the primary health facilities mostly utilised by the community and were viewed somewhat differently by participants.

Cothoza had a very complex health-seeking journey, where he made use of multiple sources of care, concurrently, in parallel and sequentially (see Figure 3.1 at the end of Chapter 3 for an overview of his health journey from 2001 to 2015). He expressed how disappointed, stressed and sad he was on the many occasions he would go to the hospital with hopes of being treated only to relapse to the same poor state of health shortly after such visits. This frustration and disappointment was evident in his trembling voice during the interviews.

Another health condition which the biomedical health systems was seen to have been limited in treating was the low sexual drive and erectile dysfunction of one of the participants. Mkhumbuleni. He expected to be treated biomedically and was disappointed when he did not receive assistance from the clinics. He said:

*These pills (diabetes pills and ARVs), someone said they leave something that is waste inside the body. It is that you notice that your member [penis] doesn't get erection. Even the doctors, the doctors they don't give you the pills to boost you they give you only these ones [laughing and trying to describe the pills]. So I use the herbs. You can feel it, if it is needed now to service myself, just to detox... Finding out that traditional medicine [helps me] (in treating his erectile dysfunction), [and] the clinic won't do anything there, so we were doing things that are done traditionally. (Mkhumbuleni)*

Mkhumbuleni was not treated for low sexual drive. Zanele, one of the nurses in the study from the clinic used by Mkhumbuleni, agreed that many patients with similar cases were also not treated. This “failure”, however, was not due to a lack of known treatment procedures or medication; rather, it was due to a lack of the necessary medication in the clinic. Mkhumbuleni eventually sought treatment from a traditional health practitioner, a health route also chosen by other men in the community to treat their sexual dysfunctions. Some of the biomedical health practitioners in the study also alluded to this use of traditional medicine to resolve erectile dysfunction by men in the community. Zanele, for example, said;

*Other [men] are open they will tell you that “I am a man, I have to detox”, and that will be a joke but you are trying to tell him a serious matter and he is making a joke out of it. Once he tells you that, he is trying to confuse your mind not to take this thing (counselling?) seriously.*

*Others just say “I’m a man, I have to detox”. He tells you just like that. You can see that ok yes he is a man. They are stubborn, you can tell him this but he will say “The clinic can’t give me something to detox, so I have to use other systems, the herbal is good for sexuality”. Most of the time they treat their sexual infections with herbal systems, not the clinic. So even if you give him counselling that “You mustn’t use herbal on HIV, use the clinic”, he will tell you that “I have got my herbal mixture that I am using”. He will take it (the use of herbs) for granted but it is disturbing his way of getting help. We have so many males with high viral load, but if you look at it yourself, you can see what the problem is. But I can’t come forward that these people are doing 1, 2, and 3 because not all of them are alcoholic. (Zanele)*

Although the South African government offers free Primary Health Care (PHC), many PHC facilities in the country have limited resources. It has been stated that South Africa continues to have “inappropriate training of primary health care nurses and other PHC facility health workers, multiple roles, heavy workload, infrequent and inadequate supervision, inequitable distribution of resources, poor facilities and infrastructure” (Ijumba 2002, 182). Due to these issues, when faced with health conditions for which they have little or no medication, the clinics become unable to assist some patients. These conditions often lead to complaints from users about the quality of services and the poor treatment and relationship with nurses, but nurses also become frustrated and dissatisfied with their jobs.

The men seeking treatment for their sexual health conditions are often aware that the clinic is not always able to treat their sexual dysfunction, either due to lack of drugs or the lack of urgency or importance linked to such health conditions. The clinics are meant to offer such services to the men freely. Hence, the lack of such services from the clinic can be regarded as a ‘violent act’ towards the men, either due to a shortage of the needed medication or to lack of interest. Zanele’s assertion, for instance, that the men claiming the need to detox, was simply an *attempt to distract* her from giving him counselling or not to take the counselling seriously, shows the lack of urgency given to such issues in the clinics. These issues are often ignored by biomedical health practitioners in order to deal with the “serious” issues of other patients, yet these issues are often very important to the men concerned. This is so because this shortage of medication, which leads to lack of some services, hinders them from becoming fully healthy. This ‘violence’ can be said to be one of the reasons behind their motivation for seeking treatment from other health systems that take them more seriously.

Such an approach can be seen as a top-down implementation of health policies and preferences, which have mostly been generated by policy makers without much impute from the grassroots. As Walker and Gilson noted, the “top-down approaches see implementation as a rational process that can be pre-planned and controlled by the central planners responsible for developing policies” (2004, 1251). Certain health concerns may be ignored or undervalued, as seen in the case of treating sexual dysfunction. With constant consideration of bottom-top policy development, however, theories and policies are based on their relevance to social services. Implementers will be required to have some discretion towards decision-making that aligns their services to variable client needs if adequate social trust in the health system is to be achieved (Rothstein 1998). Such providers have been termed “street-level bureaucrats” (Lipsky 1980) who, despite being allocated high numbers of patients, often make difficult decisions on how or who to allocate what resources to (see Elmore 1978; Hudson 1993; Walker and Gilson 2004).

#### **4.2.1 Biomedical Health Providers’ Conviction about Treating All Illnesses**

While the section above presents the experience of patients finding the biomedical health system to be limited in treating all health conditions, either due to lack of resources or poor understanding of the health condition, this section looks at how the providers expressed confidence in their abilities to treat all health conditions. These contrasting views present the difficult reality and complexity faced by the participants in this study in their use of plural

healthcare. Based on their training and experience of working with patients, most of the biomedical health providers were confident that they were able to treat all health conditions presented by patients. The biomedical health providers expressed worry that when some patients are faced with some HIV-related symptoms, they tend to believe that they have culture-bound illnesses and wish to be treated traditionally. As nurses, however, they are unable to agree with such views, instead, they make all possible efforts to diagnose and treat the patients biomedically.

*The clinic can cure any illness if the patient complies with the treatment and follows the procedures as it is. As the health providers, we know that the person with idliso is a TB suspect. It happens that he will say it is idliso then you will find out that it is TB. (Thokozile)*

Most of the nurses stated TB or symptoms of HIV or side effects of ART are often misunderstood by patients as *idliso* and they want to be treated traditionally. According to the nurses, when patients claim that the clinics are not able to treat them, this may be due to the patients' faults. Such faults may be improper intake of treatment or use of other healing approaches and medicines that disrupt the treatment and medicines from the clinic, said one of the nurses. Therefore, even when patients wish to use other health approaches, the nurses do not allow this; instead, they motivate the patients to be more engaged in their treatment.

The nurses stated that in cases where patients show HIV-related symptoms but claim that they have been infected with a health condition that can only be treated traditionally; they use certain procedures to diagnose the "actual" illness.

*Maybe if you see that your TB result came back negative then you will ask us to make transfer letter to the hospital for X-ray so that you will be able to know that you have TB or not. There are people who are using herbal medicine but they are mixing it with the clinic, others even say that I started by using faith healers, I realised that it's not working then I turn back to the clinic. (Thobile)*

The nurses stated that they are often met with patients who believe that their health conditions need to be treated traditionally or patients who engage in plural health use even when they, the nurses, see that such conditions can and should be treated within the biomedical sphere. Hence, when such patients express an intention to be treated traditionally, the nurses deter them from doing so; they then request that further tests be conducted to determine the actual illness or

cause of the symptoms experienced. The nurses stated that they are unable to encourage people to make use of health approaches that are unfamiliar to them. This has been previously reported by some amaZulu nurses who, despite their knowledge and upbringing within the traditional Zulu setting with its traditional views of health and illness, avoid encouraging such beliefs in biomedical spaces (Naidu and Darong 2015a). This position, according to Naidu and Darong, is strongly related to the nurses' wish to abide by the codes of conduct guiding their practice in such spaces (2015a). Hence, even when the clinic is unable to treat a health condition, the patient is transferred to the hospital where he or she is to be attended to by a doctor who is to conduct further diagnoses and possibly treat the patients.

#### **4.2.2 Biomedical Health Providers' Acceptance of Limitation in Treating All Illnesses**

Despite the conviction of most of the biomedical health providers in the study of their ability to treat "all" of the health issues in the community, some admitted their limitation in providing all the treatment that was required. For example, in cases where, after all the advised procedures for diagnosing patients' TB symptoms have been followed and the symptoms persist without a TB diagnosis, nurses are often left confused as to what to do.

*I saw one female this morning, she has been coughing for many weeks and we have treated her with antibiotics, we have taken sputum for investigations but everything seems to be negative, then our last hope is the doctor and X-rays. We just send patients to X-rays at Hlabisa Hospital. It's a difficult situation because after all investigations then the person is still sick and still having all signs of illness, it's quite difficult. So we keep on changing the treatment with a hope that the person will be okay. (Nthokozo)*

In many of these situations faced by the nurses, where they are in a dilemma as to what to do, the nurses make use of what Tanner (2006) refers to "critical thinking" in order to arrive at a clinical judgement. In such cases, the nurses are able to decide on the immediate need to treat the patients' "diabetes or its symptoms" while ignoring any other health-seeking options that the patient may wish to utilise. When a patient insist on using other health care options, however, the nurses offer the patients a refusal of treatment (ROT) to fill in before being discharged. Tanner (2006, 205) stated that "clinical judgement requires a flexible and nuanced ability to recognise salient aspects of a (seemingly) indefinable clinical situation, interpret their meanings, and respond *appropriately*". The appropriateness of the nurses' judgment and

decisions, however, can be questioned, depending on which health approach a user or observer may be more sympathetic and inclined to.

Aside from the difficulty with patients who show TB-like symptoms, the nurses also expressed difficulty in helping patients who have low libido, especially those on diabetes treatment.

*I am always open with my patients. Like the other one came in, he is a male, he is 46 or 43 years old, he is taking treatment for diabetes. So he told me that "Hey sister, I have been trying to have sex for more than two months. Ay it's not OK. My penis is not strong". Then I asked him if he had tried foreplay, and he said that doesn't help him. After some time, he came back and said "I just went to Durban. There is a lady; she is a nurse she told me that there is imbiza that can make my penis strong. She gave me this 2 litre, tjoh! It's working. My woman is happy and I am happy too. She is always smiling now". But because he is on diabetes [treatment], I had to check him to be sure that his kidneys are okay as he is using imbiza, even though he said he did not stop his treatment. I took everything and everything was fine. But I am not allowed to say go on with it, but it's working for you, so I think it is okay to continue taking that herbal medicine. (Nthokozo)*

Nthokozo acknowledged the shortcomings of the clinic in treating the sexual issues of its patients, especially those on diabetic treatment. The reality of struggling with diabetes and its symptoms has been well reported, especially amongst PLHIV who are advanced in age (Cheung et al. 2007; Flandre et al. 2011; Röling et al. 2006). This may be linked to the strain on the kidneys caused by both diabetic treatment and ART, which eventually affects the sexual function of those taking such treatments. The nurses sometimes allow patients to make use of an alternative health approach due to their understanding of their resource-limitedness, but also due to the "respect" for the patients' belief systems and health choice.

*I think as a health provider I have to respect a patient's beliefs. That is the first thing. I mustn't disrespect her/his health belief. But it impacts mostly those who are on [ART] treatment. It clashes if you are using more than one (health system). We just advise them that they can believe in it but not to mix if you are on treatment. Yes, they believe it is helping but it ends up destroying. If you are on treatment its end up developing, like when you put manure in your seedling to*

*make it grow, it doesn't grow the seedling only but it also grows the weeds.*

*(Zanele)*

As shown, in the extracts above, the biomedical health practitioners are often faced with patients whose ill-health symptoms appear to be related to TB, which the nurses are unable to treat, but also with patients whose health conditions, sexual dysfunction, they can treat but do not have the required medicines. In both cases, the patients often decide to use traditional healing as they believe that they can be treated using TAM. While the nurses do not agree with the patients' choice of treatment, they end up allowing the patients to carry on using their chosen health care seeking route out of "respect" for the patients' beliefs. In the case of Zanele, for example, her act of respect shown to the patients on their choices was shaped by her understanding of the cultural beliefs and traditions of the patients, but also due to her acceptance of the limitations of the biomedical health system. However, due to the nursing profession, she is unable to directly encourage such use; she can only tolerate and respect it, she said. The nurses noted, with disappointment, their inability to treat some of the conditions experienced by their patients. It was their belief that, as health providers, they should be able to take care of all the health needs of the community presented to them in the clinics.

The inability to treat certain illnesses was not an experience only related to biomedicine, as seen from the experience of the study participants. Some of the study participants also had difficulty in receiving treatment they thought would be available from the traditional health system. One such participant was Cothoza. Not only did he experience difficulties in seeking help from the hospital, but also from the traditional health system which he grew up using.

*(Shaking his head) ...after getting the mphemba stuff [a traditional medicine], I don't remember where it helped me. Seriously it didn't help me. Painting here, mixing with snakes there. Sometimes burning other things like the izinsizi (a black powder), things like that. And I realised that no, no. Sometimes drinking or licking it, things like that. It didn't make any difference that thing.*

*There is another healer whom I got, my aunt took me there. She told the inyanga "now this person is sick, we once took him there [to a different traditional healer], he is not getting well", and he said "well I will also try with my herbs". ...He was also trying. He gave me muthi and I drank it. My stomach ran every time I took that muthi. It made me to have hoped that maybe*

*this thing (swollen stomach) will go down because of the runny tummy, but no, nothing happened. (Cothoza)*

This experience of the different traditional healers' inability to treat Cothoza, the hospital's limitedness, as well as his personal disposition towards plural health use led him to seek further care from private doctors as well as from a faith healer and from different traditional healers.. His poor state of health made him desperate to seek healing from any health provision system that seemed to offer hope for healing. As a believer in traditional healing from his childhood, Cothoza had anticipated that he would be treated by the traditional healers he visited. This anticipation, however, was turned into disdain for the traditional healing system whose providers were unable to treat him. This was sustained during the course of this study: Cothoza claimed he did not want to have anything to do with any traditional healer – he would only trust his grandfather, however, he had passed away.

Any traditional healer should be able to “detect” with ease when any of the patients are having ill-health experiences caused by the ancestors when such a person has been “called” to be a traditional healer.<sup>26</sup> Such a healer is then expected to train the person, or recommend them for training, if they are unable to train them. The traditional healer visited by Lindiwe, however, seemed to have been unable to “detect” that her illness experiences were due to the “calling” she was receiving to becoming a healer.

*After the hospital didn't know what was wrong with me, that's when I was taken to a traditional person and he was the one who informed me I was well, only having illness symptoms as I was called to be a traditional healer. I stayed over at that person's house for two months and came back on the third month. He also didn't help me. They made things to make me inhale traditionally and my headache was still sore. I didn't get help because it has always been there. (Lindiwe)*

Lindiwe was surprised by the traditional healer's approach and attempt to treat her despite knowing the appropriate steps that should have been taken once a person has been “called”. The appropriate procedure is often the initiation of the person “called” into the traditional health practitioners' roles by a trainer. Truter (2007, 57) detailed this process as follows:

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<sup>26</sup> This is a process where an individual is chosen by his or her ancestors to take on the role of a traditional healer. This healing role can be as a *sangoma* – diviner, an *iyanga* – herbalist, or *umthandaza* - prophet (Truter 2007; Zuma et al. 2016).



During this time, she [or he] learns to throw the bones and to control the trance-like states where communication with the spirits takes place. On completion of the training she [or he] undergoes the *ukuthwasa* (a culturally accepted form of ancestral spirit possession when she [or he] is called by ancestors to become a diviner).

Thus, the failure of the healer to either train or recommend Lindiwe to a trainer raises questions as to his credibility as a traditional healer. One may ask if such refusal was because he was unable to admit his limitation in training her, a process which would “cure” her of the ill-health experiences she had as they were associated with “being called” or he wanted the financial income from the prolonged consultation and observations made. It has been reported that some supposed traditional healers engage in the practice of traditional healing for the financial benefits of the practice not because they have the desire to heal people according to their calling (see Abdullahi 2011; Kigen et al. 2013; Muela, Mushi and Ribera 2000). This possibility was also reported by another participant in the study when a supposed traditional healer failed to treat him.

*I went there (to the traditional healer) it was almost December [2015]. She gave me something to burn. She cut and vaccinated me for all the crazy things around here. Well I thought that her things were not working. It made no difference, yes! There was no difference at all. Even today, it is all the same. There is nothing solid she did that was clear. Well I wouldn't know if it was the spell that was working against my favour to get no help but even now, I still think she was someone who was forcing it and knew nothing about that because the person I am seeing now is from far but there is so much difference, a big difference. (Mqondisi)*

Mqondisi's experience with this traditional healer's inability to undo what he believed was a spell cast on him is similar to instances shown in research where some 'fake' traditional healers conduct bogus healing procedures as a way of exploiting people's belief in the healing system. Such practices have the potential of contributing to users deciding to either change their health-seeking to a different health system or different health provider.

In other cases, the distrust of certain health systems was not necessarily due to negative experiences from the health approach, but due to the user's lack of knowledge of the health

approach. The limited understanding of some participants of certain prevalent health approaches in the community also contributed to the complexities of health decision-making. This was particularly so when the participants were using the approaches they had doubt in, yet still wished to use different health approaches.

This use of plural healthcare is not only found amongst users of the three health approaches explored in this study. Cassidy (1998) for example, in a study which explored the use of Chinese medicine by Americans, stated that plural health-seeking was noticed amongst the participants, even when they were primary users of Chinese medicine. He said, when asked questions such as “‘what made the difference’ in their health, a majority said it was ‘definitely’ or ‘probably’ Chinese medicine... even when respondents reported using several forms of health care” (Cassidy 1998, 23). This can be because, as in the current study, although one may be unhappy with some aspects of a healing system, one still uses it while seeking help for aspects that they are not happy with from other healing systems.

#### **4.2.3 Traditional Health Providers’ Conviction about Treating Some Illnesses**

Traditional healers in this study presented views that influenced how they perceived their self-worth and role in promoting health in their communities. They openly acknowledged that they could not treat or heal all illnesses of community members and they also made use of the clinics or religious healers at times. Various factors contribute to the expertise of the traditional healers in the study, thus building their confidence in treating different illnesses presented to them. Such factors include the assistance and guidance received from the ancestors before, during and after any consultation or treatment given; their traditional training; and their exposure to different health approaches, especially some training in biomedicine. The traditional healers in the study felt their roles were legitimated by the ancestors who assisted them to identify the right treatment procedure for each patient. This, they claimed, gives them supernatural abilities in their profession. One of the healers said:

*I get told in my sleep to dig this one [herb]. When I get to the forest, haw, I find the muthi that I dreamt of digging in my sleep. I dig it and I put snuff in it then they [ancestors] tell me dig another one, dig this one and put it here... The ancestors come in my sleep and tell me that if you are working, just work like that and I do it as they say. So if you tell me that you are suffering from this and that then I will consult in my own way and I will tell you exactly what the problem is. Sometimes it is not what he [the patient] was telling me that*

*people are witch crafting him (sic). I just tell you the exact disease that is giving you the problem, not what you tell me, the cheap story. If you are lying, I will tell you the exact problem that makes you sick while you are pointing fingers at other people. (Leonildo)*

In his practice as a traditional healer, Leonildo had amassed experience of more than 30 years. With this experience and the continuous guidance of his ancestors, Leonildo was convinced that he is able to diagnose any illness suffered by a patient, even if a person attempts to lie about his/her lifestyle, which may be the cause of the illness. Leonildo's assertion about what illnesses people may be experiencing and how he is able to identify them, relates to the notion of causality as understood by patients and as understood by other traditional healers in the study. It has been shown (see, for example, Kale 1995; Moshabela et al. 2016; Naidu 2013; Naidu and Darong 2015a, 2015b, 2015c; Zuma et al. 2016) that people sometimes attribute their ill health to other community members. Leonildo believed that such assertions are not always true; people can suffer from different illnesses, natural or supernatural, yet are quick to blame others for their ill-health, he said. He said he is able to see beyond what the patients claim to be their health condition and to identify a "real" cause, which is sometimes unknown to the patients. He went on to state that such health conditions are sometimes due to people's inability to reciprocate the good deeds given to them by the ancestors, hence the ancestors stop blessing them.

The traditional healers also feel there is ancient wisdom and value to the profession as they assert that it is a long-standing form of healing in the community as opposed to biomedicine, which is more recent.

*The clinics are new, in ancient years if a person had a headache there was smoking powder for headache but you won't just make a person smoke anything, you just start by seeing how sick he/she is. I just consult, I don't pray for any person, after that I have iziwasho<sup>27</sup> to cleanse him if it's evil spirit. We have trees that God made for us. (Mzwamandla)*

In our conversation with Mzwamandla, he described three things, 'gifts from God', used before the advent of biomedicine, which he uses when healing: holy water, prayer and herbs. Combining the view that the items used and process of traditional healing is ancient with the

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<sup>27</sup> Water with powders bought from the pharmacy used by traditional healers.

role of the supernatural, God, Mzwamandla feels confident that such a practice cannot then be easily denounced or disregarded due to its foundations and support.

#### **4.2.4 Traditional Health Providers' Acceptance of Limitations in Treating Illnesses**

While the traditional healers were convinced of their ability to treat certain health conditions, they also accepted limitations in treating other illnesses. One of the major illnesses the traditional healers accepted they were unable to treat was HIV/AIDS. The healers discussed how some of their clients sometimes request “strong herbs”, even when they know that they are HIV positive and should avoid taking such herbs. The healers stated that the patients claim that they have certain culture-bound illnesses, hence wish to be treated traditionally. However, some healers had received some formal training on HIV and would therefore reject the wishes of these patients.

*Ey I won't lie to you sister [referring to the interviewer], I don't know about muthi for HIV. I will be lying. I don't know and I think there is no cure for HIV because even if I give you the books I did not see muthi for HIV and I don't know what kind of sickness it is. (Mzwamandla)*

*There is no cure for this disease (HIV), we as healers don't have the cure, we are also ill like you because if you deceive a person he will die. If you say there is an imbiza that cure this disease you will be lying, only the clinic [can treat it]. (Nolwazi)*

As opposed to the views of some of the biomedical health providers that traditional healers claim to heal HIV/AIDS, the healers in this study were fully aware of the treatment needed for HIV, which is ART. The need to treat HIV only at biomedical facilities was clear to the healers. Some of them were also on ART and were fully knowledgeable of the treatment requirements and mechanisms of HIV. Others had taken part in numerous biomedical health awareness workshops and trainings where they were taught about the origins of HIV, its transmission modes, its symptoms and treatment requirements. The false claim of some traditional healers in the early days of HIV in South Africa that they were able to cure HIV/AIDS (see, for example, Appelbaum et al. 2015; Audet, Ngobeni and Wagner 2017; Mills, Cooper, Seely and Kanfer 2005; Munk 1997) have contributed to the continuous perception that traditional healers still claim to be able to cure HIV/AIDS. However, the traditional healers in this study and most traditional healers currently possess good biomedical knowledge about HIV. None of the

traditional healers thought he or she had the ability to treat HIV/AIDS. They are also able to use certain clues to identify patients who suffer from HIV and may not have disclosed their HIV status to them.

*If a person is HIV positive, I have signs that I've learnt during my training or in the traditional healers' organisation that if a person appears like this to you it means that person is infected. If a person keeps on coming back all over again claiming that the shingles keep on coming again, that is the person that you can advise to visit the clinic. Because with that infection (HIV), a person can have the stomach ache, headache or any illness, I will treat it but if I see that mhmhm it's not getting any better, then I will tell the person to visit the clinic and see what they can do for him maybe we can talk after that. (Nknosinathi)*

Nknosinathi depended on the skills he learned from HIV training on how to identify a person with HIV. The traditional healers also depend on the guidance of the ancestors to determine health conditions, especially when a person can't accept that he or she is HIV positive after HIV-related symptoms have been noticed and spoken about by the traditional healer.

*It happens that I have [HIV] infected patients. There are many signs for this, but the person gets sweating, loses appetite, losing energy then become darker in complexion, all those are signs. He won't hide it from me, he won't hide it from the ancestors. (Velenkosini)*

*They come to us forcefully requesting that you give them the muthi. I say to them 'no I can consult myself, so I will consult now and see what else you have after umeqo'. So I just look according to my side and I will see that oh this one is coming with an attitude that I will run to give her izimbiza. I don't do that. I simply say to her 'I found your illness but before I treat you', you must first go to the clinic to run some tests'. (Nolwazi)*

Because the healers are aware of the symptoms of a HIV-positive person, they are able to refuse patients whom they suspect to be HIV positive yet who wish to be treated using certain medicines that the healers know may interfere with their ART. Aside from identifying the symptoms, the healers are also able to depend on their lived experience or consult their ancestors for clarity on their clients' illnesses. Nolwazi, who was also HIV positive, did not

only depend on her learned HIV knowledge and the guidance of the ancestors, she also depended on her lived experience as a person living with HIV to be able to identify clients who had HIV and needed treatment.

A noticeable dynamic in our interaction with the traditional healers was that all the male healers referred to their clients as males while only Nolwazi, who was one of the female traditional healers, referred to her clients as women. Although gender separation is not standard in the consultation of traditional healers as clients often choose who to consult based on their known efficiency in dealing with people's cases, clients may seek to see the most efficient of healer of the same gender. This issue however, was not the focus of this study, hence not fully explored.

When patients with HIV are detected by the traditional healers, they often respond by referring the patients to the clinics for biomedical assistance.

*So if an infected person comes, I just treat what concerns me and tell him that 'ey, other things you have to see the clinic'. You see because what must be done by me I will do it completely but what I see that I can't cure; he must visit the clinic and see what is going on. Anything related to infection I can't cure. (Nkosinathi)*

*If its umeqo, I will tell if it's not umeqo but as we now learnt, I just say 'ey you see this, start with the doctors or at the clinic to get an injection then you will come back to me', just like that because you won't hide HIV. (Leonildo)*

Both Nknosinathi and Leonildo claimed that when visited by a person living with HIV, they treated those health conditions they were capable of treating, except for HIV, which they both agreed they were unable to treat. Some of the health conditions treated by the traditional healers are HIV symptoms or HIV related infections such as *umeqo*. They may also treat other health conditions that are not related to HIV but still recommend that the clients visit the clinic for HIV testing, or treatment, if the clients already know that they are HIV positive.

Both HIV positive and non-HIV positive traditional healers in the study agreed that when consulting with a person living with HIV, it is highly important to recommend them to visit the clinic for a test or treatment first before they give them any further treatment. This, they said, was necessary as some of the clients are sometimes unaware of the necessary steps to be taken when one is HIV positive or are not fully knowledgeable of the condition. In the case of some

of their patients, however, there may be denial that they are HIV positive, hence they wish to make use of traditional medicines to treat some of the symptoms they experience. In the case of Nolwazi, most of her clients were training to become traditional healers and because she is a trainer and she insists that they visit the clinic, find out their HIV status and start treatment if necessary; only then will she carry on with the training. This was necessary, she said, because some of the activities during the training, such as vomiting or ingesting certain strong herbs may affect the trainees' health. However, with the knowledge of a client's status and treatment, she knows what activities to exclude or modify when giving prescriptions to clients.

*I say to them [HIV positive clients], 'I don't have the right to give you a traditional medicine because you are on treatment. Can you please consult your doctor who gave you pills? I can't give you muthi when you are on HIV treatment because my muthi has got something like acid and also the pills have its acid, so I will be playing with your life maybe at last you will die and they will say I killed a person, but people just lie to others' [laughed].*  
(Mzwamandla)

Mzwamandla was worried about giving clients living with HIV any herbs due to the strength of the herbs and the effect(s) they might have on their medication. He does, however, offer other forms of healing or "weaker" herbs to accommodate clients on medication. As has been shown in other studies (see Peltzer 2006; Peltzer et al. 2008; Peltzer and Mngqundaniso 2008; Peltzer, Mngqundaniso and Petros 2006; Tugendhaft 2010; Zuma et al. 2017), the traditional healers in this study also show their knowledge of HIV/AIDS treatment, how it has developed and how they understand their limitations in treating the HIV virus. For example, Peltzer and Mngqundaniso (2006, 87-88), in their study on the role of traditional healers in the intervention of HIV/AIDS/STI/TB in KwaZulu-Natal, South Africa, stated that "the majority of the (233) traditional healers in the study knew or had improved knowledge of where to obtain voluntary counselling and testing (VCT)" and "about half of the healers indicated that they had referred a patient for HIV testing" during the course of the study. Also, in a more recent study exploring how traditional healers "manage" HIV/AIDS in a rural community in KwaZulu-Natal, Zuma et al. (2017, 5) found that the "THPs were not opposed to use of ART, and they negotiated traditional healing with patients who were already on ART, advising them that they would only prescribe traditional medicines that were not strong or at a lower dosage to avoid potential drug interactions". There were the same sentiments shared by the traditional healers in the current study, some of whom were also on ART. Hence, when faced with patients who are HIV

positive, whether on ART or not, the traditional healers in this study were often cautious of what treatments to offer the patients, and in most cases, recommended the patients to their primary health care facilities for check-ups and treatment.

HIV was not the only illness some of the healers stated an inability to treat. When faced with patients with diabetes or meningitis, the healers said they recommended the clients to visit the clinics or hospitals. Nkosinathi described how he was visited by his grandfather in a spiritual form as the grandfather passed away a while before Nkosinathi was born. In one of the nights that the grandfather had visited him, he had come to inform him that he would not be able to treat the client and should rather refer the client to the hospital. He went on to take the client to the clinic himself, although the client subsequently passed away, possibility due to late arrival at the clinic.

Some of the healers were also aware of the presence and practices of false healing by people who claimed to be traditional healers but are only actually trying to make money. The worry about fake healers is related not only to the loss of finances in the process of seeking health, but also to the lack of healing from such visits. The existence of such “healers” has been noted in literature (Abdullahi 2011; Kigen et al. 2013; Muela, Mushi and Ribera 2000), whereby the supposed healers feed on the public’s wish for health, which often leads many to desperate acts and making exorbitant payments.

Aside from the complexities faced by the study participants in using the biomedical and traditional healing systems, there were also challenges faced when faith healing was chosen as a means of treatment. One participant claimed he was uncomfortable in using faith healing due to the uncertainties of its role in healing and its impact on him.

*I used to go to church at Zion, but it’s been a long time since I last went there. Sometimes it’s hard for people like us (traditional healers) to go to church. Yes, sometimes you feel like you are overacting, you end up talking about things that are private to the church. Like as I am a traditional healer, when I get to the church and see a problem inside the church I will just talk, isn’t it? But they won’t be happy with that, which is why sometimes I don’t go to church. You can go, but when they keep on singing, the spirits don’t go away and it’s the spirit that is abusing you. (Nkosinathi)*

In the initial period when individuals are “called” to become traditional healers, many have extra-terrestrial experiences, which are sometimes called “out of body experience” such as



dreams or visions (Truter 2007). In some communities or households, such experiences and the resulting behaviour are regarded as an attack from “evil spirits”. To “cleanse” the “possessed” person of the spirits and “spell”, the help of religious healers is often sought (Cheetham 1982; Truter 2007). It was about such help that Nkosinathi spoke and how he found it difficult to attend church services and activities as he is able to tell that the individual undergoing such process of “healing” might have been called to serve as a traditional healer or may be experiencing other forms of illnesses that he understands from his traditional healer’s perspective and is able to heal. Hence, he feels he would rather not attend these kind of church services where they are unable to deal with the reality of ancestry calling or traditionally-understood illnesses.

Only one faith healer was recruited and actively participated in the study. He was a preacher in the Shembe Nazareth church, and thus, promoted views about the role of faith healing in the community in line with the teachings of the church. This was the same church, whose prophet was responsible for healing one of the study participants, Cothoza, and the church leader in the study played a critical role in leading Cothoza to the prophet.

*I was poisoned by a person because he was jealous that I was chosen by the supervisor to be his cook. After he poisoned me they took me to the temple where there was the Prophet. He just blessed the holy water and said I must drink the water. After drinking the water I fell down same time. I vomited for some time until I vomited the porridge that I was poisoned with. I was healed like that with holy water and porridge. So when a person is sick, I send that person to the Prophet. He must go and get blessings from the Prophet. The Prophet will bless holy water and oil. I also do that.*

The church leader’s personal experience of healing from the prophet was his main reason for encouraging his church members to visit the prophet for any form of healing and request. The prophet often visits different temples in the community and members from surrounding temples all gather to appreciate his presence. In one of our visits to a temple where the prophet had visited, we were greeted warmly by some of the preachers, whom I was introduced to and I was assigned one of the youth leaders to guide me through the day and explain all activities to me. The expression of faith amongst the followers of the prophet that day was highly in line with the assertions made by Fundisa, who was unable to attend the visit as he was ill and had been recommended by the doctor to rest. Fundisa recommended some of the church members to the clinic.

*I recommend it because I can see it helps for a person to go to the clinic and get examined so that they can see if a person is diabetic or he is having a BP that we can't see with our eyes, and then a person will be treated accordingly.*  
(Fundisa)

### **4.3 Health Providers' Critique of other Health Systems and Providers**

Although PLHIV continue to make use of the plural health system, the providers expressed concern and uncertainty towards the various health approaches used by their patients. These uncertainties by the health providers were often from their critique and distrust of the different health systems as dangerous, “unstructured”, or an illness being new hence the health system is “not up to date” in dealing with such illnesses. This factor played a role and contributed to the complex web of medical pluralism in the lives of the participants of this study.

*Ai! I can say I am not sure if we need the traditional healers or not... There is no herbal medicine that I have heard a person saying that I get helped in using herbal medicine and get cured of HIV virus till today. Even those who say they are praying for water and conquer all illnesses then at the end, the person will get sick and come back to us at the clinic. (Thobile)*

In the narrative, which is a general representation of the view shared by most of the biomedical health providers in the study, Thobile immediately assumed that PLHIV visit traditional health practitioners primarily to seek a cure for their HIV. This assumption, however, does not resonate with the views of the participants in the study, none of whom sought the use of traditional healing to cure HIV. Such a view has been strongly presented in literature where in the early days of HIV in the country, many people thought they were cursed, poisoned or punished by their ancestors, hence sought to cleanse themselves of such curses traditionally (see, for example, Anderson et al. 1993; Langlois-Klassen et al. 2007; Liu, Manheimer and Yang 2005). Recently, however, this view has received a major shift. PLHIV and traditional healers, including those in Hlabisa sub-District (where this study was held), as shown in Zuma et al. (2017), now understand that HIV is currently not curable but treatable through constant treatments in the biomedical health facilities as well as uptake of ART. Thus, the reaction of the nurses to such patients is in contrast to the progress made in HIV treatment and education.

In further critiquing other health systems, another participant also focused on the inability of those systems to treat HIV. She also focused on how and why biomedicine is the only health approach that can and should treat HIV.

*Traditional healers and faith healers can't help in fighting with HIV/AIDS. They can't because only the whites that can heal this HIV virus or give the treatment because they know what it is, they have created it. They know the mixture that they mix to create the virus because they know that they mix 1 and 2 because they were trying to finish us as black people. So there is no illness that the clinic cannot cure. It's just people's beliefs that make them so stubborn. If you tell him to leave this and want to continue by force, he doesn't want to adopt the new lifestyle. (Nikeziwe)*

While Nikeziwe's specific reference to the "whites" as the only people that can treat HIV can be understood in direct relation to biomedicine, which is practised in the clinics as western medicine and not necessarily to whites as a race, it also touches on the debate around the existence of HIV as a western creation. This claim states that HIV was created in the west with the aim of eliminating some sections of the human race, but also its sustenance has been promoted for economic purposes by pharmaceuticals benefiting from ARVs, which are often owned and controlled by "whites", locally and internationally (Kumar 2010; Life Site News 2004; Vahdat 2012). These claims, however, have remained disputable and unfounded. Nonetheless, despite such a view by Nikeziwe, her role in promoting biomedicine as against all other forms of treatment, she stated, was because there are many illnesses that can be cured or managed biomedically and not traditionally or by faith healers, including HIV/AIDS. Regardless of the critique of the biomedical health practitioners that they have the best approach to treating illnesses, they also see other health systems, to them, as dangerous to be used.

*It is bad to mix [treatments] especially those who are on [ART] treatment. I think they are killing themselves a lot because their viral load is always unsuppressed. When they take their treatment and also use herbs, their viral load will keep on being unsuppressed or viral logical failure. Sometimes a person defaults on treatment and uses herbs but I don't see any positive difference. Others are dying, so I can see that no, this is not important. Even if a person is not defaulting, the viral load will be unsuppressed even if he is saying he stopped using other systems but the viral load will show if he is*

*continuing and the opportunistic infection will show up, you will find that he has boils, he will list many illnesses (Thokozile).*

*Some people are drinking it [muthi] because they want to raise their CD4 count, but it's not raising the CD4 only, it also raises up the disease. It ends up disturbing the blood because the disease replicates in the body, the opportunistic disease will also replicate. Some people develop sores that he/she didn't have, the illnesses that were hidden will come out. We are not saying they mustn't do it [take herbs], but they mustn't use strong medicine that will change to a drug then it will be two drugs in one blood, both of the drugs will be drunk so we educate them like that. We cannot promote herbal mixture that if you are on treatment because it is another drug. (Zanele)*

Although the biomedical health providers stated the need to respect the beliefs of the patients, they also expressed a general concern about patients who take herbal mixtures while on ART or other forms of traditional treatment as dangerous to the health of the patients. The uncertainty shared by the biomedical health practitioners hinged on the belief that PLHIV tend to “mix” ARVs with other medicines and treatments received from other health approaches other than biomedicine as a way of boosting their CD4 count or for the purpose of curing HIV/AIDS. Even when not for such a purpose, the herbs ingested remain toxic to the patients. More so, when the ingestion is done with the purpose of inducing vomiting, it places the patients in danger. Thus, such caution was not only shown towards traditional or herbal mixtures, but also towards the use of holy water by some of their patients as a way of inducing vomit. Regardless of the approach used, the nurses fundamentally rebuffed the use of any form of treatment aside from that offered in the biomedical health facilities. One of the reasons for such refusal is that when vomiting is induced, the ARVs taken by the patients get washed out of their systems with the fluids. The effect of PLHIV on ART throwing up can be problematic to the retention of the medicine in their system, hence poor effects will be made. Aside from the general concern raised by the biomedical health practitioners on the dangers of using more than one health system when on ART, they also expressed concern on some of the supposedly “safe mechanisms” that patients often implore, such as spacing the times between their ART intake and their use of other healing systems and treatments.

*Even those that say they will skip two hours and take herbs before [ART] treatment; it will be the same because you are still mixing. For 24 hours period the pills must be still working in your blood. Even if he is going to induce*

*vomiting in the morning he will be cleaning the pills out, he won't have anything in his body. He won't steam only and not induce vomiting, I think it goes together, the healer won't say you will steam only and not induce vomit, that won't happen. (Thokozile)*

*Even those saying they take the herbs at different times from their ARVs; it's not good because if they said you must take your tablet at 7 and then you take this traditional medication after, it will have an effect on the pill. (Nthokozo)*

Zanele and Nthokozo were of the view that even if patients took other medicines aside from those given to them from the clinics, they would be endangering themselves, even if they spread out the times between the different medicines. Despite this view, however, Nthokozo spoke about instances where she was made to believe that both medicines can co-exist in a person's system.

*But it can be true that it doesn't disturb because some people when you are talking to him you will find out that there are other things that he is using but when you check his file, you find that everything is fine. When you look at his blood tests it doesn't show but according to the conversation with him, he is using it but his blood test shows that everything is fine, but I don't have assurance that it all helps or not, what I know is what is done by me. (Nthokozo)*

From the narratives, Nthokozo admitted working with patients who would have been users of plural health care, especially traditional healing, but still showed no negative effects from using such systems. She said she was fortunate as the patients' clinic records did not show any worrying side effects or ill-health that may be linked to the use of traditional medicines. Despite the view of a possible co-existence of the different medicines in a user, she said she was still unable to give any leeway to such a practice as she remains uncertain about it. She is only certain of the effectiveness of biomedicine, which is the health approach she offers and wholly encourages people to use.

Another uncertainty shared by the biomedical health practitioners was that the traditional health system does not make use of standard testing mechanisms which are familiar and used in the biomedical sphere.

*My problem is that the traditional healers don't take bloods, they don't weigh their patients, they don't do investigations but they do investigations when they phosa amathambo [throwing bones]. But they don't do all investigations that give us a clue of what is happening inside the body. They just say they consult the ancestor [laughing]. Yes they consult the ancestors, yah, I know and I understand that but I cannot say they (the patients) must just go for it because there is this interaction between this two medicines. We give medication according to weight; we give medication according to blood result. We have different immune systems and so we test to treat differently and people respond differently. So testing allows us to know what to give each person. (Nthokozo)*

While Nthokozo recognised that the traditional healing system uses different forms of diagnoses as used within the biomedical realm, she insisted that she is unable to trust the practice as it can affect patients negatively. This, she felt, is the case as she stated that the lack of a “standard” in both diagnoses and treatment in the traditional healing system can be dangerous to its users who often have different immune systems and respond to treatments differently. The act of comparing one health system with another, however, is problematic as it ignores what each approach is based on. While biomedicine is built on cognitive evidence and a uniformly guided approach to each health condition, the same is not applicable in the traditional realm. Biomedicine is influenced by its general view of illness as a physical phenomenon that affects the human body. Traditional healing and health practitioners, on the other hand, recognise the metaphysical nature of some health conditions and the role of metaphysical factors, such as ancestors, in causing illnesses as well as bringing healing. This recognition however is in addition to the recognition that illnesses can be physical, hence require treatment with physical substances such as herbal mixtures or other substantial materials. Regardless of how and why patients in clinics wish to use traditional medicines, the nurses still asserted their disapproval of the approach even when it appears to be of help to the patients.

*No I don't like it when patients use traditional medicine. Yes, it sometimes suppresses the virus but its destroying you inside. They are bad, herbal mixtures are very bad. When they are throwing up, the lungs will get damaged. It will get damaged if you keep on throwing up. We train them before they start treatment but they ignore it and do their beliefs. We told them that they should not use boosters or traditional healers because he is going to die if he is mixing*

*everything. These people don't listen because we don't sleep with them in their homes. They are stubborn. (Nikeziwe)*

Although the health practitioners generally showed dislike for the use of traditional medicines, they did recognise that it sometimes helps in suppressing a patient's viral load. They stated that they are able to notice this suppression of the viral load when a patient who is known to be HIV positive and had a high viral load at a previous visit to the clinic suddenly has a low and undetectable viral load. The patients in such cases often confirm to the nurses that they had been using herbs for treating some of their HIV symptoms, said the nurses. Nonetheless, the nurses stated that this suppression is not real as it only acts as a smokescreen while preventing the proper functioning of the ARVs in a patient's system. Nikeziwe, however, agreed that there is such possibility, but it comes with a dangerous effect on the users' kidneys.

Some of the biomedical health practitioners regarded the use of health systems and medicines *other* than biomedicine as "dangerous". Nthokozo and Thokozile stated that they had ways in which they identified patients who engaged in this "dangerous" practice. There was a sharp contrast in views between what the nurses regarded as a way of identifying plural health users and the reality of the patients in this study.

*We notice that the person is a plural user with his viral load that keeps on increasing and that shows that the person is not using the treatment [ART] only. Even if he denies but we try to sit down with him and tell him about this. Some confess that they are induced to vomit or maybe they are doing this or that. (Thokozile)*

*I do have a sangoma, she is pregnant and on treatment, others are nyanga and on ARV. Definitely they use traditional medicine but I stick on my side (biomedicine). I won't say he/she mustn't take his medicine at home but...*

*Some of the other patients confessed that they sometimes use a certain traditional medicine. They are usually seriously ill and it will seem like the treatment is not working anymore, like their viral load is not suppressing. But when you are having a talk and you find that no he sometimes uses herbal medicine. Sometimes if he is using herbal medicine, he stops the treatment, so I just find out like that, hawu!! (Nthokozo)*

The nurses claimed to identify users of plural health through the increase in their viral load after a check-up. For the patients in this study, however, there was a constant record of a high CD4 count and low viral load. The CD4 count and viral load were verified from the participant's clinic files, with their consent, after they had verbally informed the study team about these significant markers of their treatment progress. Firstly, such a contrast may be due to a low understanding of how medical pluralism is practised amongst PLHIV by biomedical health providers; hence any suspicion of poor adherence is immediately linked to medical pluralism. Secondly, there could be other possible factors that lead to the occasional high viral load, but as the health care providers grapple with such possible factors, medical pluralism becomes the main factor blamed. However, patients who are users of plural health, as was the case with participants in this study, are not often detected from their viral loads; this may be the only time when they openly state their health-seeking behaviours to the nurses. This was the case in this study where the nurses were unable to recruit any such patients from the clinics into the study except for traditional healers who are easily identifiable because of their dressing, even when in the clinic. They are often seen as "problematic patients", this is so even when such healers have remained faithful to their ART, and have low or suppressed viral load and a high CD4 count. This was the case with some of the PLHIV in this study who were on ART and also active traditional healers. Such stereotypes of traditional healers, claimed Nkhosinathi, were what discouraged him from continuing with visiting the clinic after he was tested positive. He stated that the nurses immediately rebuked him not to claim that he had been cursed, for his HIV status or relating it to any ancestors' role in his life. This form of 'health violence' on Nkhosinathi can be said to have directly affected his likelihood of seeking further HIV care in the health facility, due to his fear of the nurses in the clinic. This further hinders him from self-actualisation as well as a sense of 'health peace'.

Biomedical health practitioners shared specific responses to patients who engage in medical pluralism which they generally believed was a threat to the patients' progression on the cascade of care. These responses were viewed by the patients as disapproval of their health choices. The first response of nurses was counselling on adherence.

*When we discover that the person is a plural health user, we try according to our experience and do the adherence counselling. We continue with the treatment, if we end up failing then we refer him to the doctor. The doctor will suggest taking bloods. For example, if the patient keeps on being unsuppressed viral load for more than two times, we refer that person to the hospital. They take bloods then they change the patient to regimen 2. But lately as we are*



*running short of doctors, we continue with the adherence counselling. Sometimes you find that others don't need to change to regimen 2 but it's only the adherence that is a problem. Others need to be admitted in the hospital.*  
(Nthokozi)

The nurses all spoke about the same basic steps taken when a patient shows signs of poor adherence, either due to resistance to treatment, which they said can be caused by medical pluralism, or inconsistency and sometimes stoppage of treatment. The steps however, are often taken when a patient shows signs of poor viral suppression or is experiencing opportunistic infections due to the presence of high levels of HIV virus in their system and a low CD4 count to fight the virus. Such steps do not explain what happens in cases where patients are plural health users, have remained dedicated to their ART, show no signs of adverse effects, have no opportunistic infections and have a suppressed viral load. Despite such a possibility (as with most of the patients in this study), the nurses still felt they could not encourage any use of plural health; they simply carried on with the appropriate biomedical treatment, overlooking and discouraging their plural health use.

It has been shown that biomedical practitioners find difficulty to admit their limitations or make referrals to traditional healers in situations where traditional healers have been shown to be of help (see, for example, Chigona et al. 2008; Mngqundaniso and Peltzer 2008). In such cases, despite accepting that certain illnesses cannot be treated with biomedical health facilities, they will still not refer patients to traditional healers or other sources of health care that may be of benefit. Such reluctance, as found in Darong (2015), is based on the restriction on the nurses to make such referrals, not necessarily because they are convinced of the lack of need for such referrals. Therefore, their decisions not to suggest the possible options to the patients when they are not certain of their ability to help the patient contribute to delaying the healing process of the patients. This “further cements the nurses’ conformability in medical decisions... based on the enforced norms of the hospital that the nurse may not be happy with” (Darong 2015, 96). Also, Chigona et al. (2008) noted that “it is actually illegal for Western health practitioners to refer a patient to a traditional healer”. Such referrals, however, they said, can play a major role in improving the general well-being of their users as well as the relationship between the two health approaches (Chigona et al. 2008). Aside from counselling on adherence, some of the nurses in this study ask the patients to discontinue taking ART as the drug to drug interaction may cause them severe damage. Hence, they request that the

patients either stop taking other medication or discontinue their ART until they feel they are ready to adhere to ART.

For those patients who refused and chose other forms of healing, such treatments were not geared towards curing HIV. This refusal of ART was common in the early days of HIV in the country, when people had little understanding of the virus, but today there is generally more acceptance of ART in the country. South Africa has the largest ART programme and users globally with about six of ten PLHIV on active ART (Orne-Gliemann et al. 2016; UNAIDS 2017; WHO 2015). This figure is bound to rise with the new policy of treating all HIV positive individuals regardless of CD4 count as proposed by the WHO (see Orne-Gliemann et al. 2016; WHO 2015). This high uptake of ART is primarily due to the level of HIV education and awareness gained by PLHIV- from, health providers, regardless of system, as well as general awareness in communities, including rural communities. In one of the instances in this study, where a participant refused ART and chose instead to begin a “cleansing process” with a traditional healer, he claimed he was doing this as he had “issues” that had haunted him from childhood. He stated that he was informed after his HIV test that his blood was dirty. According to his belief, if one’s blood is dirty, a traditional cleansing process is required; hence he was initiated in such a process which had four phases. He, however, stated that while he did not have a problem with ART, he was worried that the nurses would not allow him to continue with his traditional cleansing process; hence his refusal of ART during his test. The nurses had agreed to allow him to carry on with his cleansing and to return for further tests when he had completed the process. While such a revelation was at first met with shock from the study team, further interaction with the biomedical health providers shed light on these circumstances.

Discussions with the biomedical health providers revealed that there were times when the suggestion for patients to discontinue ART is also made by the biomedical health practitioners.

*When counselling the person I used to say if they still want to use traditional medicine it’s better to stop the pills. Yes, isn’t it that you want to finish with your traditional medicine first? He mustn’t take pills because he is not finished with the herbs, he must just leave it (ART). He must go and finish [using the herbs] first. When he is finished then he can come and start treatment because if he continues mixing treatment and that, it won’t help, he will end up saying it’s because of the treatment. Even his relatives will say the treatment didn’t help him. (Thokozile)*

After being counselled, if patients still insist on medical pluralism, they are often either asked to discontinue the use of both ART and the other treatments taken outside the biomedical health facility. This is to allow both the nurses and the patients to ascertain the depth of the virus in the patient's body and the effect of the practices. In some instances, the patients are asked to continue with their use of traditional medicine and when this process is complete, to return to the health facility to get tested. Such suggestions by the nurses, however, are not made with the intention of promoting medical pluralism amongst the patients as seen in an excerpt of a conversation with one of the nurses. This approach by the nurses is seen as a reverse approach of "educating" the patients of the "dangers" of medical pluralism. The health practitioners stated that they are certain that after a period of three months, the patients would be able to see the damage done by their use of other health systems and refusal of ART without mixing it with treatments from other healing approaches.

While the practice of medical pluralism may remain difficult or impossible to regulate, its manner of use often depends on the users' ability to manage how he/she uses each system and for what purpose, especially if he/she has a health condition that requires strict treatment. Successful management of how one seeks plural health can lead to diverse health routes and patterns as opposed to having a streamlined and unilateral health-seeking process. Medical pluralism gives room for unique health journeys that give room to the unique needs of PLHIV while in pursuit of good health and progression on the cascade of care.

Some of the traditional healers in the study also critiqued biomedical health practitioners and how they manage their patients and treat certain illnesses.

*... there are illnesses that cannot be cured by the clinic but it needs the traditional medicine. Mhmm there are many of such illnesses. Maybe you have lice or having umeqo or idliso, things like that, the clinics can't cure that, they won't cure those illnesses. (Nkosinathi)*

The traditional healers in the study had some distrust of other healing systems, especially biomedicine for several reasons, despite their complete trust of the system's role in treating HIV. Firstly, the traditional healers had views that the clinics, as representations of biomedicine, cannot treat certain illnesses which are either only or are best understood or treated traditionally. Biomedicine, they said, is a new health system hence it is not capable of dealing with some of the "old" illnesses. Such illnesses may be seen as culture-bound. The notion of culture bound illness was alluded to by Griffith (2014) who stated that certain

illnesses can either only be or best be explained, understood or treated within a certain cultural group. Therefore, the traditional healers asserted that using “external” or “foreign” treatment regimens will be futile for such illnesses.

Secondly, when healers asserted that biomedicine is unable to treat some of the illnesses in the community, this is related to the role played by traditional healing in the community over the years before the advent of biomedicine. Biomedicine, however, the healers said, cannot claim to be able to treat all health conditions in the community as it is a relatively new health system as opposed to the traditional health system which understands and can treat many of the health conditions in the community.

*Clinics are new; we were born before the clinics started. But when the clinics like Africa Centre arrived, they said “traditional healers, we will work together” because they found us already working, because these is our ancestors’ work. Can I ask you something now, if they can say “you, my child, have isipoliyane, how can they help you at the clinic, how can they stop isipoliyane? If there is a lady who is crying out loud, ukuhayiza at the clinic, a person who is crying out isipoliyane, what can they do about that person? They don’t know. When a person is miscarrying, I am making an example, us as healers can stand that person who is getting babies and passed away, can you stop that? (Velenkosini)*

The second perspective was that while the clinics are essential in health promotion in the community, the biomedical service providers in these health facilities remain problematic. Speaking about the attitude of the biomedical health practitioners, Velenkosini said:

*...the pills [in the biomedical health facilities] are made up of muthi that I dig. They also dig it and stamp it into a pill. So how can they say if you are using the clinic, you mustn’t use traditional muthi? But when we meet the doctors they say ‘you are very talented’, but the black matrons and nurses will say ‘you are coming with muthi to give to patients, what’s that?’ They are giving us problems.*

Aside from the traditional healers’ knowledge, belief and experience of biomedicine’s limitedness in treating some illnesses, they also sometimes distrusted the biomedical health practitioners due to how they have treated the traditional healers. One of the reasons for the

distrust between the traditional healers and the biomedical health practitioners is based on the perceived poor treatment of traditional healers and users of traditional healing by biomedical practitioners. As stated by Velenkosini, the nurses, despite being from the same cultural group as the traditional healers and the patients, do not value the healing system or its proponents and users. Another reason for the poor relationship between the two health systems is based on what Posey (1990) called “biopiracy” of indigenous knowledge.<sup>28</sup> This he says is the act of “hijacking” whereby “companies have exploited indigenous knowledge without consulting indigenous and local groups” (Posey 1990, 245). This act, which some of the traditional healers in this study, such as Velenkosini, believe has taken place in their communities, contributes to the distrust the traditional healers have towards the biomedical health system. Such a relationship between the “bearers of indigenous knowledge” and the biomedical world has been recorded in the long history of distrust between proponents of biomedicine, especially researchers, involved in the development of new medicines and local communities (see, for example, Drahos 2000; Posey 1990; Purcell 1998). A major issue in this distrust is firstly the lack of recognition for the local communities in their contribution towards the development of the new medicines that their local herbs are used for, but also the lack of appropriate financial compensation or appreciation for the provision of the herbs. It has been stated that the “knowledge about the way in which local people have used plants has always been important to collector” (Drahos 2000, 245). Hence, the use of most plants, said Drahos (2000, 245), both the “resources and knowledge about their use have been freely acquired by Western collectors from indigenous group”. Due to this distrust, the local communities who have wide knowledge of medicinal plants and other resources in their immediate environment become slow to collaborate with biomedical health researchers in the development of new medicines using local herbs or ideas of health.

The traditional healers also stated that the biomedical health providers are often disrespectful to the traditional health providers. This respect, said Leonildo, is not only about the human

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<sup>28</sup> One of the critical points raised by Velenkosini relates to the source of medicines, a concern which directly relates to the issue of intellectual property of indigenous knowledge (IK) also referred to as Indigenous Technological Knowledge (ITK), which has been widely discussed in literature (see, for example, Agrawal 1995, 2000; Brouwer 2000; Sillitoe 1998). Brouwer (2000, 1), for example, defined indigenous knowledge as one’s knowledge of “their temporal and social space”. Thrupp (1989) stated that indigenous knowledge “also encompasses non technological insights, wisdoms, ideas, perceptions and innovative capabilities” (139). To “preserve” such knowledge, local communities, says Brouwer (2000), are faced with political, philosophical, and historical problems. The philosophical dimension deals with the freedom enjoyed by academics and the free access to information for academic usage; the political dimension is based on intellectual copyright; and lastly the historical dimension seeks to promote natural preservation as a way to guarantee the dynamics of Indigenous Knowledge (Brouwer 2000, 4).

interaction between the different health approaches and their providers, but also the interaction through shared knowledge and expertise on plants. This interaction, he said, often ends up being exploitative whereby biomedical health practitioners exploit the intellectual skills and resources of the traditional healers without showing due recognition or compensation (Brush 1993; Homsy et al. 2004; Kuruk 1998; Zerbe 2005).

*You know when people go to the clinic they get told “you keep going to your traditional healers, what are you doing here, isn’t that you don’t come here to the doctors because you trust your traditional healers?” You hear that? That is not the way of talking. Our patients are sent back and they come back and tell us that they were not treated well there if they go with the transfer letter from the traditional healers. But the doctors want to know if you have consulted the traditional healer or maybe there is something that needs to be added then they give the patient there. We don’t want that, that is why we have been there and we can treat people with the doctors. What they are doing is that they took our traditional medicine and treat with it, and sell it in the pharmacy, but people are dying there at the clinic because of ancestral spirit. Regardless of these new diseases, there are ancestral illnesses. (Leonildo)*

The traditional healers maintained that they believed in the effectiveness of biomedicine and are able to refer some of their patients to the biomedical health facilities. However, due to the numerous experiences of unsatisfactory treatments of illnesses and sometimes distrustful relationships with the biomedical health practitioners, they have also developed some distrust towards the health approach and its practitioners. Leonildo was specifically unhappy with the nurses, whom he expected would be more understanding of the role of traditional medicine in the community due to the shared culture with the nurses, some of whom are from the community. He was also angry about how the nurses often send patients who are seen to be users of traditional healing, out of the clinics. This anger was exacerbated by his view on how the biomedical health practitioners take traditional herbs, process them into drugs, and sell them to pharmacies, yet are unable to treat patients adequately when they visit the clinics. Leonildo was of the view that their role as traditional healers can and should be better recognised in order for wider health promotion to take place in the community. This role of traditional healers as key role players in health promotion in their communities is critical and plays a vital role in the promotion of medical pluralism as shown in literature (see Pretorius 1999; Ross 2007; Van Rooyen et al. 2015; Zuma et al. 2016).

#### **4.4 Socio-Economic Circumstances as Contributing Factors to the Use of Plural Healthcare**

*I use the imbiza because I don't get these things (medication for sexual dysfunction) from the clinic, which will cure me so that I will be able to have my blood warm. Who will you get it from? You must go to the [private] doctor. Well, they just say go to doctors, but I don't have money to go to doctors. So it's not the same with the healer because maybe sometimes he will say mix this and that and it will come together if you do it. (Mkhumbuleni)*

The socio-economic status of health users has been linked to their motivation for using plural health care as shown in Nyamongo (2002). This is so, despite the free status of all primary health care services in South Africa. Although PHC services are provided free, the standard and range of the provided services remains limited. Thus, when patients visit the clinic with certain health conditions that the clinics either do not have the equipment and medicine to treat or do not regard an illness as a priority, such patients and their conditions are given little to no attention. In her study, Nyamongo states that some participants make use of self-treatment in order to reduce the cost of seeking “formal treatment” when they finally do. This, however, is not necessarily the same in the case of Mkhumbuleni whose PHC is free and seeking further treatment would require the use of private doctors and pharmacies. As a result, while Mkhumbuleni maintains his ART and diabetes treatment, he also makes use of herbs to treat his sexual dysfunction as they are more affordable than consulting a private doctor. Such usage is what is known as concurrent medical pluralism whereby a user makes use of different health approaches at the same time for the same health conditions, in this case, side effects of medicines taken for diabetes. Mkhumbuleni practices concurrent forms of plural health not in order to reduce the cost of seeking treatment for the same condition when he finally seeks treatment from the biomedical health approach, but because he is unable to afford any funding for such treatment which he has been told can only be gotten from a private doctor. His conviction in the effectiveness of the traditional health approach makes it easy for him to decide on using it. More so, hearing and seeing how other men were unable to get treated by the clinic for the same condition, he instead sought treatment from the traditional healer.

#### **4.5 Decision-Making Process in a Plural Health System**

The decision-making process of the PLHIV in this study in seeking health from the multiple health systems available to them is not a straight and clear process. The diagram below shows

how multiple factors come to play when choosing a health approach to treat a health condition experienced by the PLHIV in the study. These factors are the personal and external factors which contribute to the dilemma faced by health seekers in determining which of the available health approach they finally choose to seek care from.

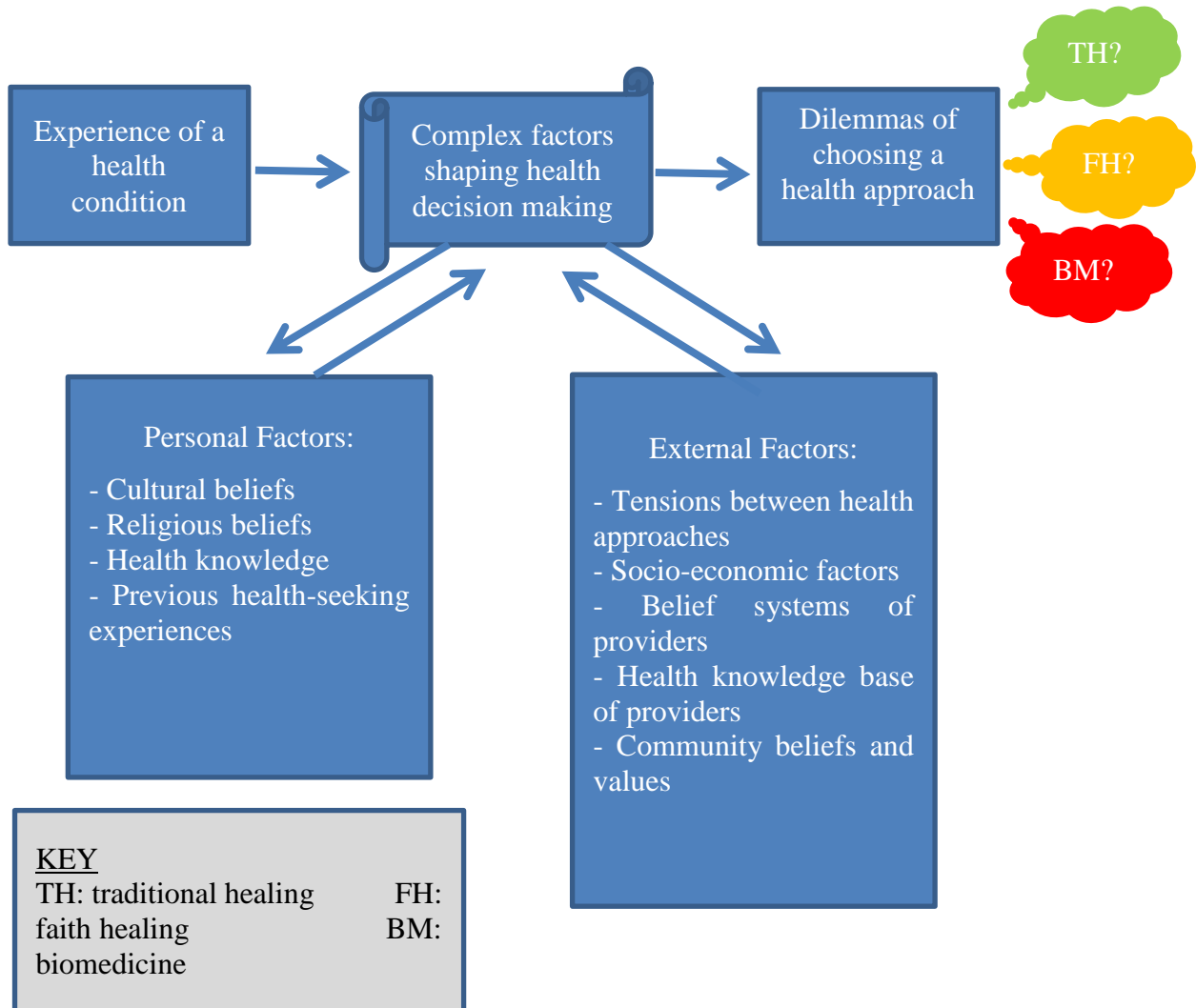


Figure 4.1: Decision-making process in a plural health system

#### 4.6 Conclusion

Due to the numerous complex factors faced by PLHIV in their quest for health, multiple health approaches are utilised, as shown in this chapter, based on the influence of one factor or another or the combination of various factors. From the narratives in this chapter, there appeared to be two major reasons for distrust of a health system. The first is what the participants, both primary and secondary, regard as the failure of a system in treating illnesses presented. The



second major reason was a lack of understanding of how a system functions, as shared by health providers. Health providers bemoaned how other healing approaches remain mysterious to them as such systems do not operate in the manner they operate their system and are familiar with. While in most cases, this view was strongly held by biomedical health practitioners towards traditional healing but also faith healing, the faith healer in the study also held a similar view towards traditional healing. Traditional healers, on the other hand, however, seemed more open to understanding other health approaches and were quick to draw the line as to when and where they feel other health approaches, especially biomedicine, is unable to treat an illness and they need to assist. These differences and distrusts are often filtered down to patients and users of the different health approaches who receive repudiation for making use of a health system that is mysterious to one health provider or another or that is incapable of treating an illness that they might have consulted such a provider for. These external factors and the health beliefs, cultural beliefs, religious beliefs and socio-economic situations of the participants played major roles in adding more complexity and dilemma to the participants in making their health decisions.

From the narratives, it can be seen that all health providers are very confident about the role they and the health system they represent, play in promoting health. This act of health promotion, however, is often met with situations that the healers are unable to treat, either due to the limitedness of the health approach, or low or lack of adequate amenities in the health facilities. In some cases, these limitations are due to the health providers' personal health beliefs and understanding. Hence, the health providers are sometimes met with situations where their expertise becomes limited. This limit to the expertise of the health providers leaves an open space for health seekers to consider seeking health from other health approaches beyond those visited. In some cases, the health providers accepted their limitations and allowed or recommended the health users to other health approaches. In most cases, however, the health providers feel they ought to do everything possible to keep the health users within a particular health system, violently interfering with the possible attainment of the patients' health peace and harmony.

This chapter has shown that the decision to engage in plural health practice is often shaped by multiple concurrent factors in the person's life and not a single factor. These factors, as shown in this chapter, range from the distrust of a health system or its health providers, the inability of a health approach to treat a certain illness, the health belief of the user and the providers, the health knowledge of the user as well as socio-economic circumstances. Therefore, in order to

fully understand and grasp the complex nature of medical pluralism and the dilemmas faced by users, their lives' multifaceted realities must be taken into consideration.

## CHAPTER FIVE

### **Support Systems and Mechanisms Used in Navigating and Resolving Tensions in Plural Health-Seeking**

#### **5.1 Introduction**

Based on the noted tensions and complexities faced by the PLHIV in the study, a major issue becomes how they navigate the different health systems and healing practices. This chapter explores the mechanisms being used in navigating the different systems. The methods of negotiating and utilising the different health services in the context of medical pluralism involves the intake of treatments or engaging in healing processes learned or sought from different health providers. Understanding this process can bring clarity to the practice of medical pluralism, especially how PLHIV are able to make plural healthcare work for them, despite the reported incidences of drug to drug reaction or development of drug resistance. It will help us understand how they are able to find peace in what seems to be a chaotic system and how they are able to ‘marry’ the different systems that are often at odds or at opposing sides of health views.

According to Moshabela et al. (2016, 88):

Conceptually, it is possible for biomedicine to adopt a scientific biological approach to attend largely to the biological aspects of disease, while indigenous and religious approaches could be used mainly to address the socio-cultural and spiritual aspects, while we resolve tensions regarding biological therapies.

However, the manner in which PLHIV make this possibility a practical daily reality remains relatively less researched, especially in cases where there is no evidence of drug to drug reaction as feared by opponents of medical pluralism. Previous chapters have discussed the various health conditions of the participants, the health systems they made use of and why they chose those systems. This chapter delves into the major question of how these users are able to use, manage, negotiate and ‘marry’ the different health services and still remain on ART, maintain a high CD4 count and a low viral load, as opposed to evidence of withdrawal from treatment due to medical pluralism. The chapter also looks at the circumstances surrounding the non-use of ART amongst the two participants in the study who refused ART.

Understanding these circumstances surrounding the uptake of ART while utilising other health approaches enables us gain clarity on how the world of medical pluralism functions and how users have been able to bridge the apparent gap that exists between the different health approaches they use. This understanding, as stated by Grant et al. (2013) and Moshabela et al. (2016) should enable us resolve some of the unanswered questions in medical pluralism regarding possible collaboration or “bridging the gap” between different health approaches in society.

## **5.2 Supporting Structures for Using Biomedical Healing System**

Being the dominant and most formally endorsed health system in the country, biomedicine was utilised to a great extent by the study participants, partly due to some of the illnesses they had, but also due to the continuous motivation for it by proponents of biomedicine. Thus, there were structures and factors in the community and the participants’ personal lives that contributed to their use of biomedicine.

One of the factors that created awareness about biomedicine and its importance in health-seeking within the study community, was ‘health education’. This was often provided by different parties, such as the clinics, health research institutes and other non-profit organisations (NPOs). This education received by the PLHIV in the study was shown to have been highly influential in their health choices.

*I think the Somkhele training has played an important role in my life. Even my siblings, I always tell them that it is important to test because if they just gave me pills without attending the class I will have a problem. Even where I was doing the training [to become a traditional healers’ trainee] I was spreading the word of testing and they were always reminding me of treatment time. They were reminding me because I disclosed my status to them to make myself free because if I didn’t disclose I would have had a problem with taking my treatment. I would have had to hide myself till when I can take them. As for my siblings, they accept me. The class that I attended in the clinic truly helped me because when I learnt about the things that were used especially traditional muthi and all that. The things that they talked about, I made sure I didn’t use them; I protected myself.  
(Lindiwe)*

Pre-ART visits and classes, as seen from our conversation with Lindiwe, played a major role in how she reacted to being HIV positive, disclosing her status to her family and trainers, maintaining a good ART programme, avoiding certain herbs as well as educating other people about the need to get tested and take the right medication. Being a traditional healer, Lindiwe made use of traditional healing methods. However, due to the education she received from the clinic during her test, she was able to learn more about what she is required to do after testing positive to HIV. This included a regular ART programme, disclosure to family members for support and maintaining a good and healthy lifestyle. Regardless of the knowledge however, other factors were also critical to when, why and how the participants made use of biomedicine.

*There was a woman who was working for Africa Centre at the clinic. She saw me crying on my first day of treatment. She asked me if I had disclosed my status at home, I said no. She asked: "Did you tell your mother about your status, how are you hiding it from the woman who carried you for nine months, she is the first person to know about this". Those words really broke my heart. When I got home, I told her [her mother] and she said "that's not a problem people are living with it, others are no more because they were hiding it and not doing well". I said to myself 'that woman helped me.' I got confidence to tell my story to my siblings and they accepted it. (Lindiwe)*

Although Lindiwe had been counselled in her pre-ART classes by the health providers, she was still traumatised about being HIV positive. This led to her receiving more support from one of the health providers at the facility. This experience shows the continuous need for support for PLHIV by their different health providers as they are faced by challenges and difficulties in carrying on with their treatment. As with Lindiwe, through constant monitoring and support, she was able to adopt a more positive outlook on life, adhere to her medication as well as maintain a healthy lifestyle while engaging in her traditional healing practice. Although the uptake of ART today has been noted as one of the major efforts in controlling the spread of HIV and managing it amongst already infected persons, HIV counselling and testing (HIV-CT) has been, for a long time, noted as an important part of the fight against HIV as it provides an avenue for infected people to be encouraged to begin ART (Weinhardt et al. 1999). The United States' Centres for Disease Control and Prevention proffers the following as the major functions of HIV-CT: a) providing a convenient opportunity for a person to learn their current HIV serostatus; b) to allow such persons to receive prevention counselling to help initiate behaviour change to avoid infection, or, if already infected, to prevent transmission to others;

c) to help persons obtain referrals to receive additional prevention, medical care, and other needed services; d) to provide prevention services and referrals for sex and needle-sharing partners of HIV-infected persons (Centers for Disease Control and Prevention 1993, 11). Weinhardt et al. (1999, 1397) noted that in the 1990s, this process was “the largest and most costly HIV prevention effort in the United States”. The positive role of HIV counselling, before testing and during treatment has been shown in literature to be of immense contribution in the uptake of ART, but also in adherence and retention in care (see, for example, Denison et al. 2008; Liechty 2005; Murray et al. 2009; Weinhardt et al. 1999).

Aside from the support of biomedical health practitioners in encouraging the study participants to make use of the biomedical health approach, their social groups also played a role in encouraging them and shaping their health decisions.

*My family takes me to doctors. They have taken me to two [private] doctors repeatedly and to another doctor once... I went to see the doctors because my sister just said she wanted to take me to the doctor because she got paid on that day. So she thought I should just be injected in town. (Sifiso)*

*I didn't inform my family members of my situation while I was doing my CD4 count. I only told all my brothers together during a ceremony and they told me I did well by taking the test and they told me they would support me where they could and I was accepted without any hassles. I told my mother and I think she conveyed the message to my father, but either way they accepted me... we are a good family. In this family we were taught to get along with each other. We don't love each other because of what someone has, we all have one mother and we all love each other too much and even the sister in-laws fit in perfectly. (Lindiwe)*

While PLHIV have sometimes been shown to fear disclosing their HIV status to their family members, this trend has changed with more HIV education and less stigma towards PLHIV. Miller and Rubin (2007), in their study amongst a group of PLHIV in Kenya, for example, stated that PLHIV often use intermediaries such as church pastors or other community strategies as vehicles for disclosing their HIV status to their families; in this study, however, it was seen that family members were often the first to know about the HIV status of the participants. This, as shown in literature (Gordillo et al. 2009; Liamputtong et al. 2009), is because the emotional support received from one's significant social network plays a critical

role in curbing the stigma that is often associated with being HIV positive. Hence, this network becomes a source of not only social, but psychological well-being for the person living with HIV (Gordillo et al. 2009). In receiving social support, one's close network is able to provide material support as seen in the case of Sifiso whose sister ensured that he received immediate treatment by providing the finances for this. Albeit the services are free, there are often delays when attending a public clinic. Hence, some people who can afford the cost of a private doctor use that option as immediate support is available from the private doctors.

### **5.3 Supporting Structures for Using Traditional Healing**

There were different factors that enabled and encouraged the use of traditional healing amongst the participants. These factors were either already ingrained in the participants from their upbringing, hence easily contributed to their health choice, or they were active social factors, such as the role and presence of family members and friends in motivating them to use traditional healing.

*My family was a traditional home by the time I was growing up. At home they were using traditional healing and they would take the child to the clinic but I grew up using traditional medicine. For example if a baby is born, he/she is taken for ukulahlwa<sup>29</sup> then after that the baby will be taken to the clinic for immunisation. (Nolwazi)*

The use of traditional medicines in the families of the research participants while they were growing up, was common. Although there were clinics, children would often be introduced to certain traditional practices *before* they were sent to the clinic for check-ups. Therefore, opting to use traditional medicines or healing practices as grown-ups, was not a difficult decision for the participants. Instead, it was an almost naturally available option. Nolwazi presented how her family's belief and use of traditional medicines showed her the positive need for a belief in and use of traditional healing. Another participant, however, presented how his family's belief in and use of traditional medicine, negatively forced him to seek the use of traditional healing to undo spells that were cast on him.

*I was told by the people I was consulting that there are people from the family that put a monster on my back. I also heard this from another healer who is*

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<sup>29</sup> A process whereby a baby is given an enema in the forest and the result of the enema is thrown in a hole dug in the forest.

*not from here and she doesn't know anything about us. Even here, next to us where I started to consult, they always said it. They said "I can see that you are not staying at home, but there is a thing that was put on your back while you were at home and you were already having it when you moved from home". I don't know what I have done to them, but I won't stab you with a knife without any reason. (Mqondisi)*

The participant was a strong believer in traditional medicine from his childhood. Thus, when given some information about the cause of his illness by the traditional healer, he opted to start using the traditional medicines *first*, without much hesitation. He chose to make use of a traditional healer having been informed by the clinic that his blood was dirty. Visiting his traditional healer and with his past experiences of culture-bound illnesses, it was confirmed to him that his blood was dirty and needed to be cleansed. This dirty blood, he said, was linked to the spell cast on him as a child. Therefore, without cleaning the dirty blood, he would remain susceptible to all kinds of health conditions. He was initiated in a cleansing process that was to last for a year which involved four stages of cleansing. The participant said he would only return to the clinic after the cleansing process to check how clean his blood has become. While he claimed to have no problem with visiting the clinic, he would only do so when there is a real need and when he is unable to treat himself with the help of his traditional healer. On hearing the participant's story, it may be assumed that his use of traditional medicines hindered his uptake of ART, especially in the context of such views by those against the practice of medical pluralism. However, the participant's subsequent assertion that he was open to ART, even if he continued using traditional healing, brings a different perspective to his approach to his HIV treatment. His assertion that he can be on ART if his use of traditional medicines is not hindered or attempts to hinder it not made by the nurses, further displays his openness to being on ART. This, however, was as long as he could also use traditional medicines to "cleanse" himself of all the "spells" that he believed were cast on him.

A participant also shared how his preference for eating certain foods he regarded as 'traditional' foods over 'modern' foods stems from his disposition towards the use of traditional medicines due to their more 'natural' and 'unprocessed' nature:

*Aah! [There was] this oil we were using, the oil from the cow yes.... We even fried pap<sup>30</sup> with this oil and eat it without any problems. Nuts were our thing and Bambara*

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<sup>30</sup> A staple meal made from maize flour.



*groundnuts. There is so much food we grew up with which develops and strengthens the body to be alright. And there is this which is called izinkombe (boiled dried maize). I still eat it and imbasha (traditional popcorn). (Cothoza)*

These ‘traditional’ foods were grown without any genetic modification and they were not processed. The participants asserted that ‘traditional foods’ are more natural, unlike some ‘modern’ foods which are often either ‘chemically processed’ or deemed ‘unhealthy’. Hence, the ‘traditional foods’ are healthier and pull one closer to one’s cultural roots. Such foods, he said are not only consumed for nourishment, but for the role they play in boosting and maintaining a person’s health. These foods, they said, were more nutritious with greater health value as they had none of the chemicals found in some of the genetically modified foods eaten by the ‘younger generations’. Although on ART, another participant, Lindiwe, a tall light-skinned 43 year-old woman, was also a believer in traditional medicines and healing, Lindiwe had a large garden where she and her mother planted vegetables such as spinach, cabbages, carrots, maize and beetroot. She commented that having a garden allows the family, made up of her elderly parents, siblings and her nephews and nieces, to avoid eating some of the ‘harmful’ food found in the shops.

Sugar, for example, as contained in bubble gum, was one of the ‘modern foods’ Cothoza mentioned. He noted how such foods contribute to weakening the teeth of youngsters, whereas in his 60s, he still has all his teeth strong and in place. The same value attached to ‘traditional foods’ is given to traditional healthcare by the participants. They regarded traditional medicines and treatments as natural and made up of items from their environment which they could easily identify. Biomedicine, on the other hand, was regarded as a foreign practice and its medicines made up of items that they were unable to determine. The treatment procedures of using testing kits and treatment machines were also foreign to them. Food in this case, not only serves as a source of nourishment, it is also maintenance of an identity as shown in literature (see, for example, Dietler 2007; Naidu and Nzuzi 2013, Rosenblum 2014). This view is similar to that of Dietler (2007), for example. She stated:

Although the consumption of food is essential for maintaining human life, that consumption is never simply taking on fuel. People do not ingest calories or protein: rather, they eat *food*, a form of material culture subject to almost unlimited possibilities for variation in terms of ingredients, techniques of preparation, patterns of association and exclusion, modes of serving and consumption, aesthetic evaluations, and so forth. (2007, 222)

Some of the participants in this study lived with their family members and in close relation with members of their community, who often played some role in influencing their use of traditional healing. These community bonds remain strong and are practised in many African communities, especially in the rural areas, such as the location of this study. As a result, the community, including one's family, often plays a major role in the behaviours and health choices of its members.

*It was grandmother who helped me to consult the initial traditional healer all the way. She knew her. It was someone they knew (silence). Yes she is from [the] local [community]. (Mqondisi)*

*They all know [his HIV status] at home. There is no one who doesn't know, except grandfather. He is a traditional healer and he is doing everything because he even gives you the injection if it's needed. Yes the injection from the clinic and also the pills things like that. He used to buy it from Durban. When he is in Durban he buys it from there even though he is a traditional healer. I do the imbiza for pile myself and sometimes from grandfather. I learnt from my grandfather and where I did the healers' training, they also taught me. Yes they taught me there. (Nikhil)*

The support enjoyed by these participants from their families was with the family's awareness of their HIV status. This support was not temporary nor did it only begin at the time of their contracting HIV; it has support that stems from most of the participants' upbringing and health approaches utilised by their families. There appeared to be no discrimination due to their HIV status. Such openness is also an expression of their confidence in the support they can get from their families, as opposed to feeling vulnerable, a feeling which is often associated with PLHIV.

Another participant spoke about how being with his partner played some role in his use of traditional medicines. Mkhumbuleni, who had a close relationship with his young partner, Nobuhle, asserted that she was aware of his HIV status, but was supportive of him using the different health systems he visited. Although to the study team, she at first denied this support, she later admitted allowing him to use the herbs because "*that's what he wanted*", she said. He said: *she knows that I am positive because she is infected. She was already infected when I got her, yes I don't hide myself to a person I am in a relationship with.* Despite their HIV status, the 61 year-old participant and his 24 year-old partner engage in sexual activity without

the use of condoms for protection. Speaking of his sexual encounters Mkhumbuleni said: *“It just happens sometimes. Eeh maybe the happiness would have been extremely over on that time [interviewer and respondent both laughed].* Due to their open relationship, both were aware of each other’s health-seeking behaviours. Although Nobuhle denied approving of her partner’s use of herbs to revitalise their sexual lives, she was aware of his use of sex enhancement herbs and supported him *“in whatever he wants to do”* and also made use of enemas, a traditional way of cleansing one’s system. Mkhumbuleni shared:

*It has happened that she feels tired saying today I am not feeling well if I can do the enema. I also give her saying ‘here it is, use it, do the enema’. Yes and use them. I say use them without any problems. Well she becomes alright.  
[Laughing]*

He claimed that his partner also brings him the herbs sometimes when he is unable to get them himself. He said: *“[when she brings it], I use it without any problems yes. If I know what it is for yes I use it”.* Nobuhle, the mother of two girls, who seemed very shy in all our visits to their family, corroborated with her partner when she stated:

*He likes traditional muthi. [Even if I am to ask him to stop] I think he wouldn’t listen to me because he is always telling me to drink them. “Drink imbiza you will be alright” [he says]. He says they clean the body and feel right. Yes he says he wakes up tired because of the pills.*

It is this sort of open relationship that allows them to be supportive of each other’s health-seeking, both traditional and biomedical health use. They attend clinic sessions together if she is around and share some of the herbs he buys from the chemist or from the traditional healer.

Aside from his partner’s support in using traditional medicines, Mkhumbuleni also reported on how his friends influenced him in going to the traditional healer to get the medicines used for treating his sexual dysfunction.

*We used to talk alone as men; that you get well with these [herbs]. This diabetes, if you continue to take pills, you find yourself that in your body you lose power. You become weak. When having sex with a woman, you will just be performing poorly [laughing]. I thought I should follow their lead.  
(Mkhumbuleni)*

During the course of the study, it was also discovered that one's social group of friends can also shape the health choices, decisions, and behaviours of a person. Mkhumbuleni, who was on diabetes treatment, was motivated by his friends in the community who talked about making use of herbs to boost their sexual prowess. On learning about a traditional healer in the community and his abilities, Mkhumbuleni who was struggling with his sexual life sought advice on how to reach the healer and he was introduced to the healer by one of the men.

#### **5.4 Social Groupings as Support Structures for Using Spiritual Healing**

The social groups of some of the participants also played a role in their decision making towards the use of spiritual healing. Siblings were part of the support structure in using spiritual health as seen in the case of Cothoza.

*By the time I was sick I came back to my family, my brother-in-law said "well, sbari (brother-in-law), let's go to the Prophet. Maybe the Prophet can help you in this thing. He is the one who will give us the direction since people get healed there. You should also go there". Well firstly I didn't go, I delayed but after I got home, I went straight to my brother-in-law. He took me there. That was my first time to see the Prophet. (Cothoza)*

With the help of his *sbari*, Cothoza came to know and appreciate the rituals of the Shembe Nazareth Church. These rituals are similar to Zulu traditional rituals as there are strong links between the Zulu culture and the Nazareth church. Cothoza was pleased to find that the rituals and celebrations in the church were the same as those he had grown up with as an amaZulu. Hence, when ill, although he experienced some initial resistance, he was able to listen to his brother-in-law's suggestion to visit the Shembe Nazareth Prophet. This visit was the first step in his experience of healing due to the impact of the holy water and oil received from the Prophet. Aside from the motivation received from his brother, Cothoza was also motivated by his religious leader to seek help from the Shembe Nazareth prophet. As a church leader with personal experience of healing from the prophet and with many of his church members also being healed by the prophet, he was certain that Cothoza would be healed too. The 68 year-old, who had been a church leader for more than 30 years, expressed delight in the role he played in many of his church members' healing, including Cothoza.

#### **5.5 Navigation 'Mechanisms' and Strategies for Using Plural Healthcare**

Despite the complexities, tensions, dilemmas and varying support structures for the participants in the study, they were able to develop mechanisms and strategies that allow them to navigate these complexities in seeking improved health. These navigation mechanisms are not part of any formal health-seeking procedure, nor were they approved by some of their health providers. Nonetheless, to survive the complex system of health-seeking and still maintain a good quality life, the participants developed approaches that enabled them to use a variety of health services and maintain a healthy lifestyle. One of the strategies used by some of the PLHIV in the study was the complete avoidance of ‘strong’ herbs that would interfere with their ART or induce vomiting.

*As I am telling you that I learnt from the clinic, I was not taking imbiza before even at the [traditional healers’] training. I heard that if I drink imbiza it will clash with the pills. So even at the training I asked them not to drink imbiza because it drains the pills before the time to take another pill, then you will be like a person who did not take treatment. Some people also use enema, but I don’t because of my health condition. I am afraid of doing it because I know that after using enema it will give you a running stomach and for sure it will also drain the pills. So I told my trainer I will do other things and I also asked him that if it is treatment time I will leave everything and go to take the pills even if it is busy or else if the car comes to give me the pills I will leave everything and go to that car. At the training we were waking up early to do igobongo. In fact you wake up early to talk to your ancestors not to throw up. But I asked them nicely that I won’t throw up, I would only eat the foam, and you don’t even drink the igobongo water. The foam can raise the spirit.*  
(Lindiwe)

Some of the activities required in traditional healers’ initiation, said Lindiwe, and would clash with biomedical treatment conditions. Ingesting certain herbs, using enemas and throwing up were the major practices she highlighted as being in conflict with her treatment procedures. Ingestion of herbs might interfere with the ARVs as she was taught in the clinic. Hence, she sought permission from her trainer not to ingest these, use enemas or participate in throwing up. Instead, she informed her trainer of her health condition and of the need for her to take her medication at a particular time, a request which was granted by her trainer. Lindiwe continues to maintain these views about what traditional practices to avoid when a person is on ART.

*...I was not doing the throw ups and not using the enema with his [her trainer] stuff. I told him that these things are not supposed to be done by a person on treatment. I was also using pills most of the time because I heard at the clinic that if it's eight, it must be strictly eight and I chose this time myself.*

*Even the people I train come here and I look at them that there is a calling but it's not going alone, there are other infections. I say to them "now we will change the way we do things. We won't throw up we will just go to the ancestors' altar and chew igobongo". If a person said he has TB, I don't want him to throw up. It's easy to do to other people what you have experienced. Because if I didn't go through this HIV infection maybe, I will end up having dead people in my house saying that people must throw up and do all that whereas you are making a person worse. (Nolwazi)*

Nolwazi's experience during training was similar to that of Lindiwe and she was able to negotiate with her trainer. Due to her experience as a person living with HIV and her experience during training, she was able to identify which of her trainees might be HIV positive, encourage them to get tested and regulate their training activities to accommodate their HIV treatment.

Another approach used by some of the PLHIV who were unable to completely avoid the intake of herbs due to their profession as traditional healers, was the partial use of the herbs they give to their patients.

*My healer told me "you don't need to get muthi that will cause more harm to these things; it must be muthi that will cool down slowly. Like you mustn't take it as if you want to get better then you overdose it. Just measure the necessary amount to start with because if it happens that you take more than what you are supposed to take, you will die". (Mqondisi)*

This was the advice given to Mqondisi when he visited one of his traditional healers while he had TB. This view was corroborated by one of the PLHIV in the study who was also a traditional healer. Speaking about how she makes sure people on treatment take mild *muthi* and do not throw up their pills, she said:

*If you are giving herbs to a person, you can show that person using a spoon in front of her then she will see that it's not poison. There is something that we give them but it's not hot stuff. When she is going to throw up, you inform the*

*person that it's not something hot, but it's just something that if a person has a problem and need to throw up, he can just take two cups of muthi as long as the muthi gets inside the body. It's not that he is doing throw up to take out the gall like people who are saying "I am taking out the gall with hot stuff". It's just something that is weak and it's just a cleanser. Some people don't believe that it's working, but it is working ... it's mild but it's working. I am not a person who throws up because after I was diagnosed, I sat down and burnt the incense and told them [her ancestors] that I have this problem. So I will do the igobongo, just to touch and eat the foam, bathing my body with it and that. I was taking the treatment when I was there [at the initiation] because I disclosed my status to the trainer and he accepted. (Nolwazi)*

In order to accommodate their HIV treatment patterns and medication, these traditional healers had to devise means of carrying out their practices. This ranged from the intake and recommendation of mild herbs rather than the strong herbs to the use of only certain herbs in different ways. For example, *igogongo* can be used for bathing instead of ingesting the liquid. The liquid, said Nolwazi, is too strong and can affect the ARVs in her system. Thus, devising other means of using the herbs with the permission of her ancestors, she was able to navigate the complexities of her health situation and professional expectations.

Taking ARVs and traditional medicines at different times, especially for those who ingest herbs or other forms of traditional medicine, was another strategy used by the PLHIV in the study to negotiate the experienced complexities of medical pluralism.

*Traditional medicine and biomedicine can work together, but the problem is with the pills that I got from the clinic. At the clinic they said I must use it in different times, like the ART treatment, I take it in the afternoon around seven and maybe in the morning I can take the traditional, but after three in the afternoon I stop everything getting ready to take ART treatment at seven. they are not disturbing each other because when it's time to take [ART] treatment, the traditional one would have already worked and done its work in the body then the [ART] treatment will take place the whole night. (Nikhil)*

*I say to my clients [who are on ART], 'Because I noted that you are taking treatment at 8, so you must wait two hours then maybe you chew igobongo two hours before so that when you are taking pills, the pills mustn't be disturbed*

*by anything'. I also use the clinic and also use traditional medicine as I am taking my pills at 8 so if I'm going to chew igobongo, I will do it at 6 but you just eat the foam then you rub it on your body when 8 comes to take pills, I will be finished with my igobongo.*

*What I notice is that if I stop using igobongo, my ancestor's illness will come up again thinking that I neglected them but its life's situation and nowadays situation and I did report this illness to the ancestors saying that 'I don't have a perfect life, so I won't do some things, avoiding to get sick. I am now not a person who can cook muthi and throw up and all that. No I am not doing that. (Nolwazi)*

The excerpts show a conscious effort to adhere to the ART programme but also fulfil certain professional roles as traditional healers or treat certain health conditions using traditional medicines by spacing apart treatments. The participants' efforts show an intentional development of treatment patterns devised to 'survive' the complex situations they are in, being believers and users of traditional medicines and being PLHIV who need to be on ART. This complexity was alluded to by Nolwazi who stated that being a traditional healer, she was unable to stop giving and using traditional medicines completely; doing that can lead to health conditions caused by the ancestors, showing their disapproval for her actions. All she could do was inform the ancestors of her health conditions, living with HIV, and the requirements of such a health condition, if she was to take her treatments and remain healthy. After doing this, she is then able to develop the means to conduct her traditional rituals while also ensuring that the rituals and medicines do not affect her ART.

Nikhil, another participant, stated that both health approaches can work together, yet emphasised that the problem was with the medication from the clinic and the instructions that come with this. The major instruction was the non-mixing of the ARVs with any other medication or the avoidance of taking these while on ART. This view and disagreement with the instructions from the clinic, especially the complete avoidance of traditional medicines and treatments, was shared by many participants. Most of the participants found the instructions around the use of ARVs from the biomedical health providers to be uncomfortable and sometimes impossible to keep, if they are to remain the traditional believers that they are. They are sometimes almost faced with a choice between their traditional beliefs and practices and the uptake of ART. Such expectations create tension in the health users as they 'violently'



ignore the belief systems of the user. However, the health users' mechanisms of survival were an attempt to have the best of both worlds without necessarily choosing one over the other.

Although some of the nurses in the clinics showed some understanding of the participants' complex situations, most of them were still uncomfortable with their patients' use of plural health care. This was because such a practice is not in line with the biomedical health policies that guide the practice of biomedicine and the conduct of the nurses. The participants, however, were of the view that both health approaches can be utilised concurrently without any issues. One of the participants, however, noted that the nurses often advised him not to use traditional medicines close to the time of his CD4 check-up dates. This was because the herbs have an ability to boost a person's immune system and they may affect the results of the check-ups. He has diligently adhered to this request. Nolwazi was able to draw from her experience of using the different 'survival mechanisms' she had developed and has been effective in helping other users of plural health who are on ART.

## **5.6 Conclusion**

In the course of seeking health, the PLHIV in this study had multiple support structures in their use of plural health. These structures were either systems, bodies of beliefs or family structures. At different stages of their health journey, the support structures change and reliance on one or the other changes. Such changes were due to either the health conditions experienced or the strength of the system in their lives at that time.

Although not standardised or formally acknowledged, there are mechanisms utilised by PLHIV who are plural health users as shown in this chapter. Such users are able to depend on their support structures, which shape their health views and decisions, in managing how they make use of the health approaches available to them in relation to their health conditions. The participants made use of multiple health approaches while maintaining consistency in their cascade of care. They were consciously aware of their health conditions and the requirements for treating them. Such awareness enables the participants the ability to negotiate health-seeking patterns, in order to gain maximum health status. The study shows how, despite moving from one health system to another, they still are able to return to using that which they

are more familiar and comfortable with. Through this process, the participants were able to express their agency in health-seeking decisions. This allowed them to successfully develop 'navigation mechanisms' through the complex system of medical pluralism.

This chapter shows that efforts to make use of multiple health approaches are not unconscious or without some awareness of the possible medical implications. Instead, the mechanisms are derived through a conscious decision made from the available knowledge about the different health approaches and their requirements, but also with the help of certain support structures. Knowing and understanding how these mechanisms function with a larger population and over a longer period, can possibly help in resolving the existing gaps between the different health approaches used by plural health users. It can also pave a way for the possible development of an approach towards plural health use that can lead to collaborative treatment between different health approaches.

## **Conclusion and Recommendations**

### **6.1 Introduction**

Despite the advanced knowledge in HIV/AIDS research, currently, there is still no cure for the disease. WHO has, however, stated that with “effective antiretroviral (ARV) drugs can control the virus and help prevent transmission so that people with HIV, and those at substantial risk, can enjoy healthy, long and productive lives” (WHO 2017). Whether on ART or not, it has been shown that PLHIV make use of multiple health systems in their health-seeking (see Colvin et al. 2014; Govindasamy et al. 2012; Miskelly 2006; Moshabela et al. 2011; Mugglin et al. 2012; Pantelic et al. 2015; Rosen and Fox 2011; Saethre 2007). Such an approach to health-seeking has often been blamed for contributing to the failure of HIV programmes. The practice of medical pluralism is said to discourage HIV testing, uptake of HIV care and adherence to ART.

The use of different health systems has been linked to diversity in world views, including health. Individuals often have the opportunity to make health choices and decisions that may not necessarily be in line with the dominant health systems (see, for example, Naidu 2014; Naidu and Darong 2015b; Vaughn et al. 2009). This use of plural health is shaped by multi-dimensional factors, personal as well as external factors. These factors include the belief systems of the PLHIV, the societal context and societal beliefs and practices, as well as the roles played by the health approaches and providers they use. These different factors often lead to tensions in health seeking.

PLHIV who are plural health users face complexities in decision-making and treatment-seeking. However, they are able to make conscious decisions as to how they make use of the available health approaches. This can be seen as an expression of agency by PLHIV regarding their health choices. As Halligan, Bass and Oakley (2003) stated, personal choice is not often present in many biomedical processes whereby the patient becomes a passive recipient of an already developed model and this affects progression in their health-seeking behaviour. Plural health users, however, are able to express their agency, thus showing their creative ability because “people are rational, aware, and self-creating agents of their own health, who can behave in the pursuit of self-interest... influenced by consciously chosen goals” (Chin, Monroe and Fiscella 1999, 319). Hence, this study sought to understand the experiences of PLHIV in

using a plural health system, particularly exploring the tensions and complexities they face in this usage as well as how they are able to negotiate and navigate the tensions and complexities.

## 6.2 Critical Review of Findings

Several findings have emerged from this study, which are directly related to the experience of the PLHIV in the study as well as the health providers on how they engage with the phenomenon of medical pluralism. Some of these findings relate to how the PLHIV use plural health and how they face and resolve tensions and difficulties they face in their practice of medical pluralism. Some of the findings are linked to health providers' views on medical pluralism in their patients.

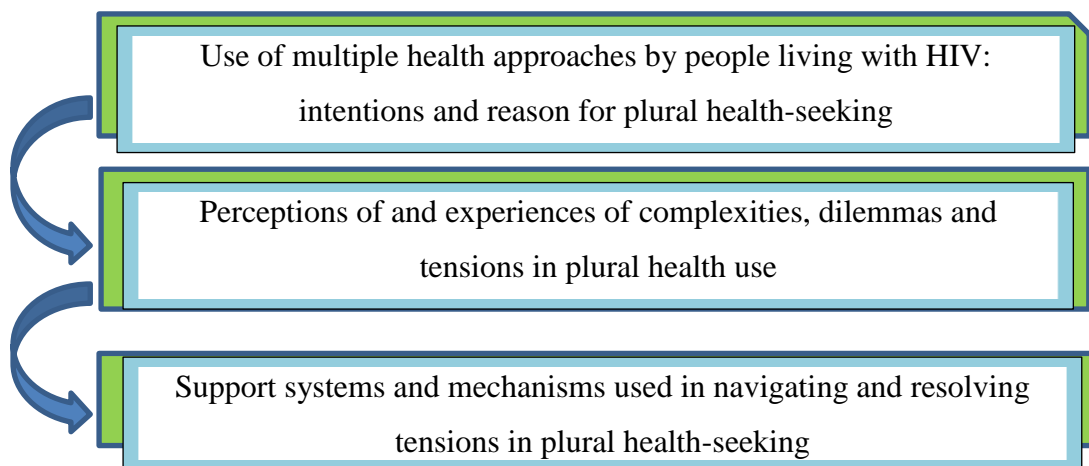


Figure 6.1: Critical stages in the practice of medical pluralism

The first finding was on the health systems used by the PLHIV in the study and their intentions and reasons for using the different health systems. The three major health approaches utilised by participants in this study were the traditional approach, faith healing and biomedicine. However, reasons for using each of the health approaches varied. The participants mainly used the clinic and hospitals in treating health conditions such as HIV, TB, diabetes, body pains, asthma, kidney failure and epilepsy. To complement the care received from the clinics and hospitals, the participants also made use of private doctors when they needed expedited services and pharmacies when they had minor health conditions such as flu.

Aside from these biomedically-related health service points, the participants made use of traditional healing for certain health conditions. Traditional healing was sought for conditions such as erectile dysfunction, fits, *umkwebhelo*, cleansing 'dirty blood', shingles, TB, piles, and kidney disease. Although the participants made use of the traditional healing approach for these

health conditions, it was not in all cases that they were healed. In the case of Cothoza, for example, who visited two traditional healers at different times in an attempt to get his swollen stomach treated, both healers were unable to help him, prompting him to seek further care from private doctors. However, in other cases, the participants found relief in their use of the traditional health approach.

The use of multiple health systems, as shown in the study, may not necessarily be peculiar to PLHIV. Individuals experiencing other illnesses also make use of these systems. In the case of PLHIV, however, there has been more stringent rejection of the use of plural health from their biomedical health providers, who are their primary HIV care providers. The use of the different health approaches, as seen in this study, is highly shaped by factors that are either personal or external to the participants. Such factors include the participants' beliefs on health and illness, but also the beliefs of their health providers, or the state of the health services, as well as the health views and practices of their communities. It was discovered that the participants use the different health approaches for illnesses they were certain could only or best be treated by the chosen health approach. This, to a great extent, was a display of their agency in reaching a sense of health peace while fighting against the violence, tensions, and complexities they face due to the rejection of their health behaviours by some of their health providers. This evidence challenges the notion that they are a socially vulnerable population and may not have the full agency to express themselves or their choices (see, for example, Ayres et al. 2006; Brashers, Neidig, and Goldsmith 2004; Gordillo et al. 2009; Gruskin, Ferguson and O'Malley 2007; Ingram et al. 1999; Liamputtong et al. 2009; Miller and Rubin 2007; Skinner and Mfecane 2004). Hence, when experiencing illnesses that they believe could be treated traditionally, they often preferred to seek traditional help rather than attempt seeking help from the biomedical health facilities or the faith healers. This same agency of choosing health systems was also shown when they wanted to use biomedicine or faith healing. Thus, healthcare was always sought from a health approach that the participants believed had an ability to treat them; however, when there is failure to treat such a person, they often sought healing from other health approaches that are available in the community.

The second major finding was regarding the perception of and experience of difficulties, dilemmas and tensions in the plural health-use of the primary participants in the study. This finding shows the role of the multiple factors that contributed to their choice of using medical pluralism, but also, how the presence of the different factors often led to complexities,

dilemmas and tensions when making any health-choice. While there were multiple health approaches available and used by the plural health users in this study, this usage was often riddled with tensions and complexities of knowing what health system to use, for what illness, and at what point of the illness experienced. These dilemmas were often preceded by the complex factors faced by the health users. Such complexities, as seen in the study, are made up of personal and external factors. The personal factors include the cultural beliefs, religious beliefs, health knowledge and previous health-seeking experiences of the health users. Due to the cultural or religious backgrounds of the participants, they become conversant with certain health beliefs and approaches, which they rely on and use when ill. Such factors include the use of traditional healing, biomedical health knowledge, religious beliefs, community health values, as well as socio-economic situations. These factors played out mostly when there was uncertainty regarding certain health approaches due to either their beliefs or their previous experience of the health approach.

Commenting on how PLHIV make use of plural health, one of the nurses, Zanele, stated that as a health provider, she “respects” the patients’ beliefs. Thus, when a patient wishes to use health approaches other than biomedicine, she does not actively deter such a patient, although she does not agree to such a health decision. While Zanele is able to show some “respect” towards her patients varying beliefs in other health systems, other biomedical health providers were completely against the use of any health system apart from biomedicine. Hence, when faced with patients who practice medical pluralism, they would express their displeasure. This clash of beliefs often leads to tensions and dilemmas for the health users. This finding portrays the role of external factors, in form of health providers in medical pluralism and how they shape the health decision-making of plural health users. The views of the health providers on their roles and the roles of other health providers in treating HIV or PLHIV, was seen to be critical in either promoting or reducing tensions and complexities for plural health users. Hence, refusal to attend check-ups or collection of ARVs by some PLHIV who practise medical pluralism may not necessarily be because they prefer the ‘other’ health systems over biomedicine in their treatment of HIV; instead, their fear of the nurses’ and counsellors’ criticism and attitudes can, as shown in this study, deter some patients from visiting the biomedical health facilities for their treatment.

The traditional healers in the study had great conviction in their ability to treat certain health conditions for the following reasons: because they receive guidance from their ancestors; they know which herbs to use for each health condition; and because traditional healing is an old practice hence can treat health conditions that existed prior to the advent of biomedicine. As

also shown in other studies (see Peltzer 2006; Peltzer et al. 2008; Peltzer and Mngqundaniso 2008; Peltzer, Mngqundaniso and Petros 2006; Tugendhaft 2010; Zuma, Wight et al. 2017), the traditional healers in this study admitted that they were unable to treat all health conditions experienced by the community members, especially HIV/AIDS. Hence, when they identify patients who may have these illnesses, they refer and encourage them to visit the clinics for check-up and treatment. This, they said, they are able to do because some of them have undergone some basic training on identifying symptoms of illnesses such as HIV/AIDS and TB. They stated that they are able to see the signs and symptoms of HIV in their patients which they learned from the workshops and trainings they had attended.

The biomedical health providers in the study also expressed certainty and conviction regarding their ability to treat the illnesses of members of the community. However, they also admitted that in certain situations, they were unable to successfully diagnose or treat their patients. In these cases, some of the nurses reluctantly suggested the use of other health systems to the patients. According to the nurses, such moments leave them feeling compromised; they are filled with moral dilemmas between keeping to their professional code of practice and making the ‘undesirable’ choice of suggesting other sources of healing to their patients. Such moments place them between their personal and professional beliefs, but they usually consider the well-being of their patients as the main factor in their decisions. As shown in Darong (2015, 93), “the goal of any clinical decision otherwise known as ‘clinical judgment’ taken by a nurse, is not technical, rather, moral in that the activities carried out by the nurses are not important in themselves but important based on how they contribute to the wellbeing of their patients”. Thus, some of the nurses are sometimes able to condone the use of other health approaches, even though they do not personally make recommendations for such usage. Others are able to “partially” suggest the use of other health approaches (which is against their professional code of conduct) to their patients. This is particularly so when they feel they are unable to watch the patient go through tests and treatments that would not have any positive health outcome.

The faith healer in the study, like all the other health providers, expressed conviction in the role played by faith healing in the community. The main “healer” in the church is the leader of the Shembe Nazareth Church, also known as the Prophet. All the preachers in the Nazareth church, however, also play a role in linking people who need healing to the prophet and sometimes conduct the prayers themselves. It was the conviction in the powers of the prophet that led the faith healer to link one of the study participants, Cothoza, to the prophet.

The considerations in making clinical decisions were seen to be based, not only on the health conditions of the patient, but also on what the health provider believes is needed. This belief by health providers is often shaped not only by the professional training of the health providers, but also by their personal, religious and cultural beliefs, as stated by Naidu and Darong (2015c). While the clinical or health decision made by the health provider may be with positive intentions towards assisting the patients, some of such decisions may contribute to the tensions and complexities faced by the health users, thus increasing the psychosocial violence faced by plural health users.

The personal factors that contribute to the health decisions of the participants, while within the reach of the health users' control, have often built from exposure to some belief systems and experiences. The external factors on the other hand, are often beyond the reach and control of the health users. Both factors create a wide range of complexities for the health users, thus they experience dilemmas in choosing a health system. Some of these moments of dilemmas are due to the inability of health approaches to treat certain health conditions and health providers' distrust of other health approaches. The uncertainty shared by some of the health providers towards other health providers, was evident from one of the participants, Thokozile, who said that the patients may go on praying, if they wish to, but when they discover that the prayers are not able to treat the HIV, they will be welcomed back to the clinic. Such views, however, often do not necessarily represent the intentions of such health users. As seen from this study, the participants did not seek the help of health providers other than biomedical health providers for the treatment of HIV/AIDS. Instead, they made use of treatments for illnesses that they either knew or believed could only or best be treated by such health approaches.

The third major finding was linked to the support systems, mechanism and strategies used by the PLHIV in the study to navigate and create some sense of 'harmony' or way to resolve the tensions and complexities experienced in the use of plural health care. Despite the complexities, tensions and dilemmas faced by the plural health users in this study, they were able to devise mechanisms to resolve the tensions while accessing all the health services they needed, regardless of the source. As has been reported in a study which sought to understand how traditional health practitioners engaged in the "management of HIV/AIDS" (Zuma et al. 2017), which described some mechanisms used when treating patients who were HIV positive, the PLHIV in this study reported on their personal experience of using various mechanisms in navigating their complex route of seeking plural health care. The navigation mechanisms were as follows: complete avoidance of strong herbs and vomiting; partial use of herbs; and



separating when treatments from different health systems are used. In order to develop such mechanisms, however, there were several support mechanisms in place for the plural health users. These included the influence of their traditional beliefs and practices, traditional foods, social groups, such as family and friends, religious leaders, and health education from biomedical health practitioners and researchers. For example, Lindiwe, who was on ART and also a traditional healer, stated that she always told people about the need to go for treatment at the clinics, despite being a traditional healer. Her views were based on her exposure to the dangers of non-adherence to ART, biomedical health education through training and her traditional beliefs. Although she was a traditional healer, she managed to merge her practice of traditional healing, which involved her use of traditional medicines, with her ART programme. She is obliged to taste the medications she gives her patients but manages to ensure that these medicines do not affect her ART by taking only minute portions of the medicines, especially if they are “hot” and not “weak”. These findings show that the plural health users in the study were aware of their health conditions and that they consciously made health choices in order to gain maximum health from the different health approaches available. Despite the existing tensions between the different health approaches they use and the complexities they face in their health-seeking, they were able to negotiate their way through self-choice of treatment approaches and for different health conditions. This ability portrays the agency of the participants who are active and conscious users of plural health systems. Contrary to common beliefs, they play an active role in their healthcare choices and are not simply passive recipients of health services.

### **6.3 Interpretation and Discussion of Study Findings**

The findings of this study provide evidence of the complexity in the practice of medical pluralism. These complexities exist primarily due to the nature of the study community, that is, its belief systems as well as the state of the primary health delivery. Thus, there are multiple factors that play a role in a person’s choice of health system, for particular illnesses and at particular stages of the illness. A plural health user may make a decision to approach health system A or B, or A and B concurrently, in parallel, or sequentially. Major factors in this choice process are the personal and external factors of the user. An overview of these factors in the practice of medical pluralism, learned from this study, can be found in Figure 6.2.<sup>31</sup> Like a tree, the practice of medical pluralism has hidden roots, which are not visible, but can only be

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<sup>31</sup> While the sketch of this tree was sourced from the web page Coloring Pictures (2017), I segmented and labelled the tree for the purpose of interpreting medical pluralism, as practised by the participants of this study.

imagined or conceptualised; it has a visible trunk, branches and leaves. In practice, however, as shown in literature and in this study, some of these segments of medical pluralism, which are either visible or imaginable, are either ignored or treated as though they are non-existent. They are the personal and external beliefs of plural health users and the experienced dilemmas in making health choices. More focus has been placed on the illnesses experienced and the visible acts of medical pluralism and their supposed effects on the plural health users. The often ignored crucial factors in the practice of medical pluralism, however, play key roles in shaping the world-view, health beliefs and subsequently, behaviour of users of medical pluralism.

The personal circumstances of the user, which include their health beliefs and knowledge, their cultural beliefs, religious beliefs and previous health-seeking experiences, as non-visible factors, have an impact on predetermining choice of health approach. Certain illnesses are generally seen to require treatment from a particular system. For example, while a person may be keen on using the biomedical health approach when he/she is HIV positive, he or she may immediately seek the help of a traditional healer when experiencing nightmares on a continual basis. Such a person might have grown up with a traditional belief that such experiences are linked to sorcery or bewitchment; hence, they need to be attended to traditionally. Such an individual may not immediately seek the help of a psychologist at a biomedical health facility, until a point is reached where the traditional healer can longer help. Even in such cases, if such a person also has a strong religious belief in ‘deliveries’ from ‘evil spirits’ or from ‘unseen bondages’ through prayers and the use of other religious items such as water, oil and candles, such an individual is likely to also make use of a faith healer. In some cases, such plural health users may move from one health provider to another, all within the same default health approach. Only when such default health systems of the plural user fail to heal the person, will further help be sought from other health approaches. In cases where the health services require some form of financial input, a less expensive option is most likely to be considered first.

Added to these personal circumstances shaping the health choices of plural health users are the external factors they are faced with in their health journeys. Such factors, as shown in Figure 6.2 (that follows), include the existing tensions between health approaches, the socio-economic situation of the user, the belief systems, health knowledge and approach of the health providers visited and the communal health beliefs and values. These circumstances are often beyond the control of the users. The tensions between the different health provision systems, which exist due to differences in health views and approaches, can cause a plural health user distress when he or she wishes to use different systems for different aspects of the same illness or for different

illnesses. This distress is particularly evident when a health system requires exclusivity rather than a combination of health services from various health approaches. The health beliefs of the health providers visited also play a key role in how a plural health user makes health choices. Some health providers are relatively “open-minded”; others, however, discourage “mix matching”.

The communally held views towards health and illness can also influence a health-seeker. In a community where there is a strong belief in sorcery, for example, the likelihood of some illnesses being linked to sorcery will be higher than in a community where biomedicine, which is more evidence-based and empirical, is the dominant approach to health. Within all these external factors also lies the socio-economic status of the plural health user. This often contributes to how they make use of the available health approaches in the community. They can immediately seek help from a private doctor, who is often more resourced, but also more expensive than the public health facilities and services. In this study, for example, it was seen that participants who had more financial stamina were likely to make use of private doctors than public health facilities, as opposed to participants with less financial stability. The various dilemmas, uncertainties and tensions faced by the plural health users in making a decision on what health approach to use, are often ignored by the critics of this form of seeking health. Regardless of the factors leading to the different levels and moments of dilemma faced by the plural health users; in the end, they are able to make conscious decisions on which health approach or approaches to use for which illnesses or aspects of an illness. This conscious decision, which is symbolised by the leaves in Figure 6.2, signifies their agency and ability to develop practical mechanisms that allow them to navigate the complexities of using the plural health system.

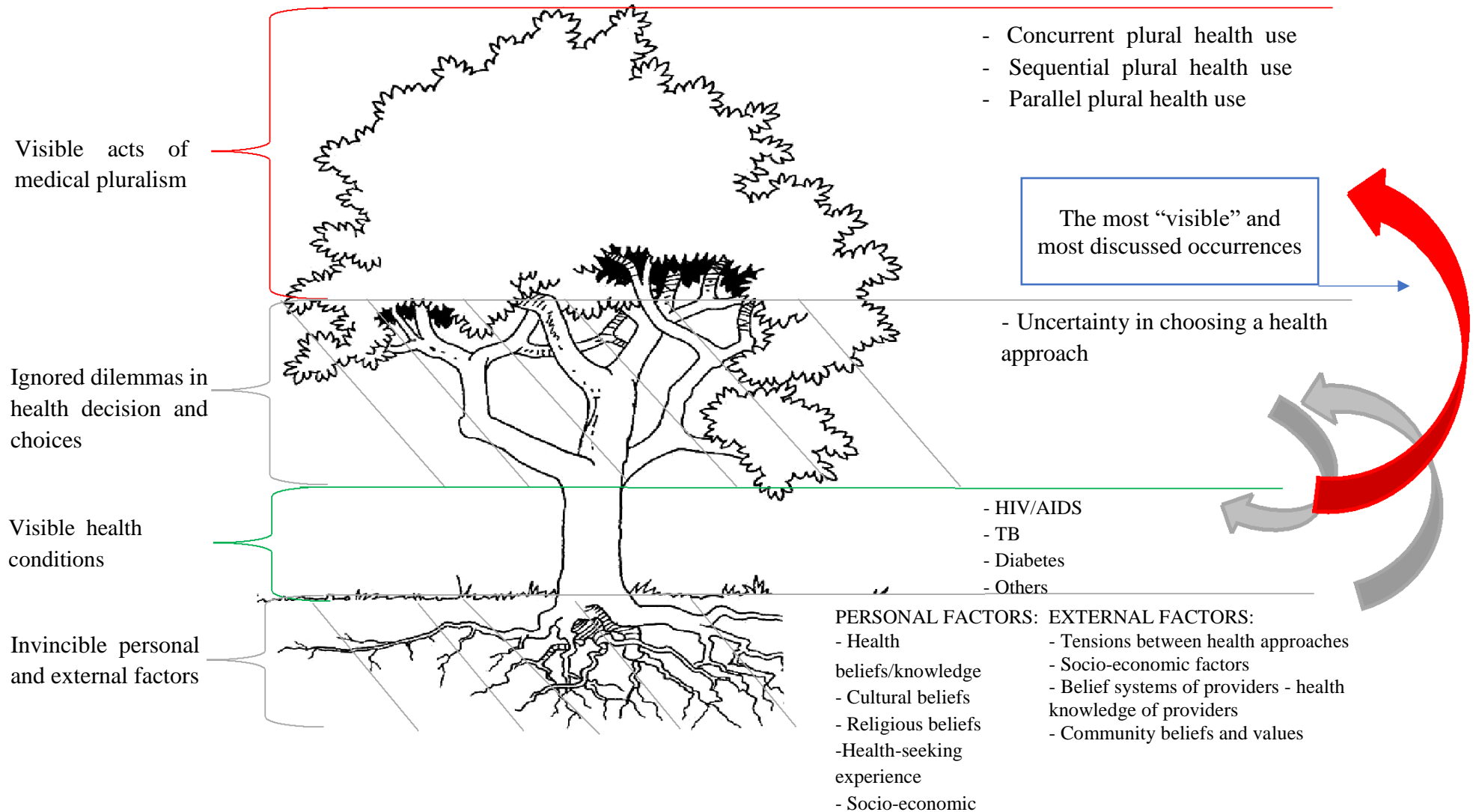


Figure 6.2: The plural health user tree: Multiple influencing factors in plural health (Tree sketch from the web page ‘Coloring Pictures’ 2017)

The following characteristics were identified in most of the participants in the study:

The first aspect of the plural health-seeking behaviour observed amongst the participants was the attachment made with health systems that were introduced to participants in their childhood. Upbringing in secure settings with supportive family members who introduce the participants to traditional healing was shown to play a big role in health beliefs. The sense of security received and the comforting support, enabled trust towards a particular health system. Trust, in this case, is achieved from the combination of both security and comfort/support. Security, in this case, can be seen as the feeling of assurance in the effectiveness of the treatment/healing approach/medication received by a user. Comfort/support can be seen as the feeling of empathy shown to and received by a user from a provider of a health service, or the care expressed in the delivery of a health service.

The second aspect of the plural health-seeking behaviour of the study participants was the immediate use of the default health system when ill. The trust in a health system makes this system a person's default health system. Hence, when ill, health is immediately sought through such a health system with the assistance of one's support structure, family and friends. The participants in this study often had sufficient support from family members when seeking health. However, the deficiency experienced in the different health approaches, such as misdiagnoses from a hospital or lack of healing from a traditional healer, created mistrust towards such health approaches.

The third aspect of the plural health-seeking behaviour of the participants was an observation that they were able to make an attempt to 'try out' new health approaches when faced with difficulties in their default health system. Hence, participants were able to attempt different health approaches to the ones they had grown up with. This can be regarded as a 'leap of health belief'. Such a leap can be attributed to either the advent of new illnesses that cannot be treated in the default health system or the availability and relative affordability of the new/different health systems and the society/government's constant pressure on community members to make use of the provided health system, facilities and services. Growing up, most participants did not have such pressure or emphasis on the use of the biomedical health system. Rather, they grew up in apartheid South Africa in areas designated for black South Africans, with little or no access to biomedical health system and services. Even when this was available, it would have been at a prohibitive cost. The traditional health system, which they grew up with, however, was readily available with no fixed cost, was effective and the providers were familiar and trusted community members.

The fourth aspect of the plural health-seeking behaviour of the study participants was the use of private doctors as an additional source of health. Although they were also part of the biomedical health system, the use of private doctors was primarily because they were believed to offer patients better attention and care than would be received at a public health facility. This can be related to the need for security and comfort; hence, the private health sector is trusted and used by some people, especially those with good financial standing. While such health providers are not situated within an established institution as a hospital, their services are also considered biomedical. The participants often received some form of treatment and diagnoses which led to a sense of security in and comfort from the providers.

The fifth aspect of the plural health-seeking behaviour of the participants relates to a possible return to 'default' health systems by users of plural health when they are not fully satisfied with the newly explored health approach. When total security and comfort was not found in the new health systems explored, participants return to their default health system with the support of family members. This foundation, however, had already been shaken and called into question due to the lack of satisfaction in previous visits. This shaken foundation was partly due to the breakdown in trust of a health system; comfort and security were not evident as the systems were often unable to offer total treatment.

In the sixth health-seeking aspect of the plural behaviour, it was noticed that despite returning to one's default health approach, other factors may still contribute to dissatisfaction with the health approach. Hence, where there are more options of health systems, users are often likely to explore further, for health satisfaction. With unhappiness in the newly explored systems and dissatisfaction with the default systems, participants were keen on widening their health-world based on the number of available health approaches in the community. Maintaining the use of new health approaches required adequate support structures or extensive delivery of care from the system in order to keep the user attracted and attached to the system, lack of which leaves the user considering a switch to another system. These were some of the common identified characteristics amongst the users of plural health in this study. These characteristics, however, are likely to apply to users of plural health in different settings and with experiences of different illnesses to those found amongst the plural health users in this study.

The observed characteristics of the plural behaviour of medical pluralism amongst the participants of this study can be expanded to enable a general understanding of the principles embedded in the characteristics and practice of medical pluralism. Trends indicate that people are able to develop trust in a health system, which can often become their default health system

if they experience comfort and security here. When ill, such individuals are likely to immediately make use of their most trusted health system, which is their default health system. When a person experiences ‘incomplete’ treatment from such a health system, while it may disrupt their trust in the system, it will however, not make them discard the system totally or dismiss any possibilities of using it further. Rather, they will still maintain the use of the system for certain aspects of their illness and make use of other health systems for other aspects of their illness that the primary health system does not fully offer them. This different usage can either be for different aspects of the same illness or for entirely different illnesses or health conditions. Experiencing complete difficulty and inability to find any help or feeling completely dissatisfied with the system, on the other hand, can spur a person to completely desist from using such a system and make use of a different health system.

In some cases, the introduction of a system of health to a person from their childhood, biomedical, traditional or spiritual healing, creates a feeling of ‘safety’ in the person. Thus, a person is naturally drawn to using such a system, even when older. The continual effectiveness of the familiar system of health solidifies the person’s confidence in it. External factors, such as socio-economic reasons and health beliefs of health service providers, however, can cripple a person’s use of a familiar health system. In cases where there is an alternative familiar system which promises similar health services, but at a more affordable rate or with better provider relations, a person is likely to switch to this. If there is no familiar alternative system, however, a person is likely to explore until a suitable alternative is found, thus leading to multiple switches between different systems. While external factors may contribute to a person’s use of a particular health system, the intrinsic personal desire can be a stronger drive towards making use of different health systems, concurrently, sequentially or in parallel. Thus, while the use of plural health amongst PLHIV may be influenced by external factors, their intrinsic desire to seek health plays a larger role in their health choices.

These principles of medical pluralism as observed from this study, however, can be challenging when they are to be implemented in people’s daily healthcare seeking routine. The first major challenge faced by medical pluralism proponents is the questioning of the effectiveness of various healing systems, especially systems other than biomedicine. This questioning often leads to a rejection of a particular system. The second is the acceptance of the existence and effectiveness of more than one health system. However, proponents of this second school of thought still express some reservations in plural use of systems due to the fear of counter-indications. Thus, while a proponent of this second school of thought may not deny that there are health systems other than (especially) biomedicine that are used by PLHIV, they will be slow to recommend or endorse the

use of such systems. The third view occurs when (mostly biomedical) health practitioners show some ‘understanding’ and ‘sympathy’ with their patients for their belief in, and use of plural health systems and *secretly*<sup>32</sup> allow or encourage some of the patients to seek help from other health practitioners.

In the first two challenges, despite the level of ‘understanding’ and ‘sympathy’ towards medical pluralism, there is a concern about ‘mixing’ different medications from the different health systems. In these cases, it can be argued that the inadequate knowledge of medical pluralism as a health approach leads to doubt and subsequent dismissal of the system. This dismissal has been shown to be common, particularly amongst some biomedical health practitioners.

While there are many negative views towards medical pluralism, some health practitioners, across all health systems, as well as the general populace, show some understanding and acceptance of medical pluralism. In this instance, which is rare, providers are able to allow the use of different health systems with advice on when and how users should engage in this practice to allow for the full effect of their ARVs and other treatments (see, for example, Naidu and Darong 2015a; Moshabela et al. 2016).

#### **6.4 Views and Recommendations on Enabling a Better Health-Seeking and Delivery Environment**

Some of the findings of this study show aspects of health systems which the PLHIV in the study viewed as hindering adequate health-seeking and delivery, or contributing to the difficulties faced in health-seeking journeys. Hence, addressing some of the issues raised by the PLHIV as reasons for their inability to receive adequate care from the different health systems they visit is critical. Addressing some of the issues raised can contribute to better quality health care provision from the different health systems, but also possible healthcare collaboration between the different systems in the context of medical pluralism. The recommendations and views can contribute to discussions and further research for both the development of each of the health systems available and used in the community as well as a better understanding and practice of medical pluralism.

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<sup>32</sup> As shown in literature, some biomedical practitioners have been able to move beyond denying the existence and efficacy of health systems or healing practices other than biomedicine (Naidu and Darong 2015a; Moshabela et al. 2016). This ‘understanding’ and sometimes recommendations are mostly carried out in secret as the ethical code of conduct of such practitioners does not allow them to engage in endorsements of healing practices other than biomedicine.



The first perspective on how the different health systems used by plural health users can be improved, based on the issues raised by the participants of this study, is the building of capacity within each of the health systems. Part of the factors contributing to the complexity of seeking health, especially through medical pluralism, as shared by the participants in this study, related to the lack of adequate services from the available health systems. This shows a need to improve these systems in order to increase their possibilities of meeting the health needs of their users. To meet some of the challenges that contribute to patients 'switching' from one system to another, capacity building can be promoted within each health system. This will enable the health providers of each system to have better knowledge and skills on the approaches used in the system. This improved knowledge and skills should in turn contribute to the quality of service provided to users of such systems, and possibly reduce the level of 'switching' between different health approaches.

The issue of staff shortages, which was seen as one of the major issues in biomedical health facilities, directly relates to patients' need for sufficient attention when seeking healthcare, a service that cannot be provided in health facilities with staff shortages. Due to the low number of staff members, users of the biomedical health facilities often spend long periods in queues waiting to be attended to. Time spent with health providers is often limited. Hence, health users often prefer health systems with providers who are more available and who spend more quality time with them (Hewson 1998; Parle 2003; Truter 2007). In order to address this issue, what has been suggested in numerous studies (see for, example, Daviaud and Chopra 2008; Hudson 1993; Walker and Gilson 2004) is the need to address and increase the number of well-trained biomedical personnel. This need can be addressed through supporting the training of biomedical professionals at different levels who will then be available to tackle the high volume of patients and health-needs in biomedical health facilities as well as in communities. While this effort may be the direct responsibility of the South African government, corporate and private individuals, who are also part of the communities and beneficiaries of the health facilities, can contribute towards addressing these training needs through individual sponsorships and provision of materials to both health practitioners' training and health facilities. The provision of the materials could ease some of the reported issues by the study participants, which included the lack of adequate treatment in some of the health systems and low staff presence.

#### **6.4.1 Sharing of Knowledge and Skills amongst Health Practitioners**

Some of the findings from this study, such as the varying views about the same procedure or an illness amongst health providers, show the need for the sharing of knowledge and professional skills amongst health providers across the different health systems. This process of knowledge sharing can contribute to the development of the capacity of the health providers to tackle the health issues they face in their different systems. The need for improved knowledge and skills amongst health practitioners was specifically discovered amongst traditional healers, some of whom had opposing views on their understandings of certain illnesses treated by traditional healers. The contrasting views were mainly on their understanding of the causes and treatments of some health conditions. Such a contradiction was seen in some of the traditional healers' view of shingles. While some believed that it is caused by supernatural factors and can be cured traditionally, others were of the opinion that this condition is a symptom of HIV and cannot be cured traditionally. Such differing views often contribute to the complexities of medical pluralism as the tensions experienced by the users are not only due to inter-system differing views, but also due to some intra-system views. Thus, the health seekers are left unsure of which approach to use for certain illnesses. To curb such disconnects, the government or non-governmental health organisations can organise workshops and seminars for traditional healers, where they not only discuss their role in conjunction with other health systems and providers external to the traditional health system, but also amongst themselves as traditional healers. Such workshops can be facilitated by recognised and trusted traditional healers in the country, who could assist in overseeing the development of clarity amongst the traditional healers. This could allow healers to gain some knowledge and skills from each other and as such strengthen their understanding of the different health issues they treat in the community, thus strengthening their practice and role in treating such health conditions.

Beyond the development of skills and knowledge within each of the health approaches, it was noticed in the course of the study that there is a need for knowledge sharing between the providers of the different health approaches. Doing this will allow the different health providers to understand the views of other providers. One of the participants, for example, stated:

*My concern that I have is that we learn about this [identifying PLHIV], but not all of us. Most of the healers didn't get that chance and that knowledge... because if you look at other traditional healers, they still believe that people have idliso. We must have all the traditional healers so that doctors and nurses*

*will explain to them so that they will understand. We once had a meeting with the clinics talking about TB; they said TB at Somkhele is killing many people. We must discuss this issue so that we can conquer that demon of infecting each other. Because of this training to a small group of people, many healers still don't know that if a person comes to him and say he is losing energy that such a person must visit the clinic, but healers are still lying saying that no I can help you with that. (Nolwazi)*

This view of training healers by Nolwazi was also shared by some traditional healers in relations to the trainings organised by AMREF. These trainings were focused on teaching traditional healers about some biomedical techniques, such as identifying patients with specific illnesses and being able to recommend patients to biomedical health facilities. One is, however, left wondering whether it is only traditional healers who need some knowledge of biomedicine or if biomedical health practitioners also need to have some knowledge of traditional healing. The need for all health providers in the community to have some knowledge of other health systems in the community is critical as this will aid them in understanding what their patients are offered when they visit other health systems. They should also be able to understand why patients make these visits and use these health systems. Such training can be organised by the government as well as non-governmental institutions that focus on improving the health life of communities. Health providers from the different health systems can be brought together in workshops and seminars where experts in the different systems, who also ought to be providers from such systems, are able to coordinate a process of teaching and learning in the forums.

#### **6.4.2 Health Providers' Disposition towards Collaboration**

The different health providers used by PLHIV in this study were influential in their patients' practice of medical pluralism; they either supported or were against the practice. This influence mainly emanates from how each health system treats illnesses. While the details of how the healing processes are conducted and the materials used may be different, due to differing practices and principles, the aim of each system is healing, whether it be physical, mental or spiritual. A primary step towards collaboration lies in the need for the different health providers to understand what is believed and practised in the other health approaches. Understanding the different health systems used by members of the community will allow for a deeper appreciation for the existence of the health approaches by the different providers and possibly motivate for collaborative work, all focused on healing patients.

The traditional healers in the study were, compared to other health providers, more open and keen on collaboration with other health providers. This was partly due to the exposure they had received on biomedicine, but also from their personal experience of the value of using biomedicine for some of their own and their patients' health conditions. The traditional healers in the study had confidence in their ability to treat certain culture-bound illnesses that they felt could not be treated within biomedical spaces. Such a view was the result of experience in treating certain health conditions that are either not understood or cannot be explained biomedically. Also, with biomedicine being a more recent health approach than the traditional health approach, the traditional healers were of the view that a new approach cannot necessarily have answers to all the 'old' health conditions that have been treated successfully through traditional means previously. They, however, also admitted that there are illnesses that they are unable to treat.

A major shift has been shown regarding the views of traditional healers towards HIV/AIDS and other related illnesses that appear not to be able to be treated traditionally. Such illnesses, they said are the 'modern illnesses' such as HIV/AIDS. Hence, traditional healers have been shown to be more open towards learning about other health approaches and possibly collaborate with health providers from other health systems. Because they also use the biomedical health and faith healing approaches when ill, the traditional healers said they are comfortable recommending their patients to biomedical health facilities for treatments they cannot offer. Added to this view was the assumption that HIV/AIDS was *created* by the West, hence only the West, using western healing systems, can treat that which it created. This however, has been shown to be an assumption made by opponents of biomedicine or western societies without any clear evidence. Hence, the traditional healers treat patients for illnesses they are confident of treating and the patients to other health systems, such as biomedicine and religious healers, for illnesses they are not confident in treating. Having some of the traditional healers also living with HIV and on active ART brought more light as to how they are able to use the different health approaches, as they cannot avoid the use of traditional medicines and healing while being healers themselves.

Peltzer (2001, 6), for example, stated that traditional healers often refer patients with "AIDS, diabetes, asthma, tuberculosis, mental illness, sexually transmitted diseases, epilepsy, stroke, bone fracture, high blood pressure and others" to biomedical health facilities and providers. This attitude, however, has not been identified amongst health providers from other health systems, especially biomedicine. As a result, the traditional healers expressed dismay at the attitude of the biomedical health practitioners, especially nurses, who seem to make conscious

efforts to downplay the roles of the traditional healers and their efforts in promoting health in the community. The mechanisms the healers stated, as either part of their survival mechanisms or recommendations to their patients, open ways for possible collaborative healing between the different health approaches used by patients in this community and other communities. One of the healers, for example, stated:

*The faith healers are good, I am also a Christian because most of the things God reveals to them like seeing things in your dream, there is nothing bad that I know about them they are working very well. We also like the clinics because there are new illnesses like HIV and all that. When I consult, the ancestors will tell me that this person is HIV positive. We have papers to show that a person should go to the clinic but those at the clinic, because they are claiming education, they don't accept a person from the healer, and they take us for granted. But if a person is HIV positive there are signs that are showing that means you don't have to hold that person; transfer him to the clinic. I also visit the clinic because there are illnesses from west. I am able to differentiate whom to consult, the healer or the clinic, if I see that this illness needs the clinic not the healer I just go to the clinic. (Velenkosini)*

The practical impact of such 'appreciation' is that despite some of the beliefs held by the traditional healers regarding some illnesses, they are able to make a shift towards the patients' safety, taking into consideration the implications of some of their practices. This shift is evident in how some traditional healers who previously used unsterilised sharp equipment, such as knives or blades on multiple patients (see Peltzer and Mngqundaniso 2008; Peltzer, Mngqundaniso and Petros 2006), have recently been more cautious. The use of a new razor blade for each patient by traditional healers is one such concessionary practice.

In some instances, traditional healers spoke about the correlation between traditional healing and faith healing. This correlation makes them understand and appreciate the role of faith healers in health promotion and their ability to conduct collaborative healing. Because of such views about faith healing, Nkosinathi, for example, was able to assist health seekers with wide range of health conditions. Such expertise is one of the possible ways in which the different health providers are able to express understanding and appreciation of the expertise of other health providers.

Biomedical health providers generally appear not to be interested in learning about or collaborating with other health approaches (see, for example, Chipolombwe and Muula 2005; Madiba 2010; Mbwambo, Mahunnah and Kayombo 2007), a view also shared by some of the biomedical health practitioners in this study. Opposed to this view, however, and as also shown in some literature (see, for example, Peltzer and Khoza 2002; Peu 2000), some of the biomedical health practitioners in this study were open to possible collaboration with health practitioners from other health systems, even though reluctance is generally evident. One of the nurses, from her personal and observed experience of how traditional healing is practised in the community, said:

*Some years ago, there was no cure for shingles at the clinic, many people didn't get treatment for shingles so people were using traditional healers to vaccinate the shingles and it stopped. They could vaccinate it and it disappeared without taking any pills because there were no pills for it. That means there are illnesses that they can cure. So you can't say it's only the clinic [that can treat people] because there are things that they [traditional healers] can do successfully, especially me, I have seen shingles' problems. I used to see that it can be cured if they treat it traditionally and also the other diseases called eczema and ibala.<sup>33</sup> They say you will use the enema if the child has eczema and you can see that there are things that they (traditional healers) know. It's better than giving patient pain killers that is not going to help because it only stops pains but the shingles continue growing. (Zanele)*

The views by Zanele and other nurses about the possible role of traditional healing in treating some illnesses in the community came from both their personal experience as well as their observation of patients who were treated with traditional medicines. These experiences allow Zanele to make more critical clinical decisions, understanding that there are other existing and efficacious healing systems in the community aside from biomedicine. However, due to the policy requirements of biomedicine, they are unable to encourage patients to make use of any other healing approach other than biomedicine, despite the providers' knowledge, belief and experience of the effectiveness of the health approach.

Noting the openness towards understanding other health approaches and openness towards allowing patients to use them or conduct collaborative healing, one wonders why such options

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<sup>33</sup> This is a black dot that usually develops at the back of an infant's head.

have not commenced in the country. Although the cultural upbringing of the nurses also shapes their thinking and health views, exposure to different health approaches and their role in healing, thus makes them better judges as to how efficacious the different health approaches are. Thus, views regarding understanding other health approaches and possible collaboration as shared by these street bureaucrats ought to be taken more seriously. This is so because they are the ones in daily contact with the users of plural health and have better understanding of the health situations of the patients.

The spiritual healer in the study also showed willingness towards collaborating with providers of health from other health systems.

*I used to say government has opened this hospital; I am not against it because government is working in its own way. This illness is treated by government (biomedicine) so I allow the person to go to the clinic to get pills for his illness. It's advisable that as you are under government you must use government; therefore, it is not good that I as a Preacher to lead you in a bad way saying that you are a Christian you must not use clinics. Because even in Christianity as we go for gathering, we go with the clinic so that if a person is unwell on the way, you go inside the clinic and get treated. (Fundisa)*

Fundisa's emphasis was around how he encouraged his church members to use the clinic as he understood the role played by the clinic. He had no issues with people making use of the clinic as they also seek the services of the clinic when they are having pilgrimages, where they walk for days to the mountains. The mobile clinics are used in such journeys to treat church goers who develop any health conditions that need immediate assistance.

In order to enable possible collaborative work of the different health providers used by some PLHIV, there is a need for developing the patients' awareness of the different health systems and the types of health conditions they are able to treat in order for them to seek and receive timely and efficient health services. Health education has been defined as "a combination of learning experiences influencing behavioural changes, producing changes in knowledge, attitudes and skills needed to maintain and improve health" (Beranova and Sykes 2007, 22). This education, as Kaptein and Wienman (2004) showed, often needs to be initiated by the health provider as patients rarely ask questions that will build on their health knowledge. Patients often leave this role to the health providers as the professionals of such health approaches and the only ones who know what is best for the patients. With grounds for mutual

understanding and possible collaboration between the different health approaches in the study community, creating an atmosphere of ease and health awareness among the health users will be critical. As the primary users of the plural health care, PLHIV ought to be given all possible education and awareness on how different factors can lead to the health conditions they experience, the different health approaches in the community and their health choices.

On the health conditions experienced by community members, PLHIV need to be aware of the origins of such illnesses, the infection mechanisms, the symptoms and the treatment procedures. Having such knowledge will prevent health-seekers from receiving misguided information about their health conditions, an act that can lead them to seeking care at the 'wrong' health system. This can be done through community engagement programs organised with the collaboration of the different health providers in the community. Having a united and collaborative approach will create a sense of ease amongst the health users in openly expressing their health views, which in some cases need clarification and guidance. Aside from educating health users about the different health conditions existing in their community, they also need more education about the different available health approaches. Educating the health users will enable them to understand the possible role of each of the health approaches in their health-seeking journey. Such a move will clarify some of the conceptions and misconceptions health users may have towards the different health approaches.

While this development of the health users' knowledge around health conditions and health systems needs to be spearheaded by established health institutions, governmental and non-governmental, health users also need to be motivated towards becoming inquisitive and not passive health users. Therefore, any moment between health users and their different health providers ought to be used not only for the delivery of health services, but also for educating and enlightening the health users. Such conversations between health providers and the users will build an inquisitive and open mind-set in the health users whereby they are able to comfortably discuss their health views and use with their various health providers.

## **6.5 Conclusion**

Despite the progress in the understanding and treatment of HIV/AIDS, some challenges continue to exist in the willingness of people to know their status, take up treatment on time when found to be HIV positive, and remain in care towards achieving a suppressed viral load. Amongst other possible factors, plural health use of PLHIV has been regarded as a contributing



factor to these challenges. Despite this link between medical pluralism and persisting challenges in HIV care, it has been shown that some PLHIV continue to make use of plural health care. This is more so in communities where there are multiple health care approaches. In such communities, individuals, regardless of HIV status, make use of the available health approaches for different health conditions and at different stages of their ill-health experience. This study, thus, was aimed at understanding the experiences of PLHIV in their use of the different health approaches. The study firstly shows the different illnesses and health approaches used by the participants in the study and their motivation for using each of the health approaches. It was discovered that their understanding of such illnesses, which included their views about the causes and best treatment approach for the illnesses, contributed in determining what health approach they used for treating the illness. For some health conditions, even when they believe that they could be treated within a biomedical facility, for example, they may still opt to be treated either by a spiritual healer or a traditional healer.

The study further shows how the participants are met with various dilemmas while they traverse the different available health approaches in the community. Such dilemmas, as shown in the study, are caused by the complexity of factors that remain interwoven; some were personal to the participants while others were external factors. The personal factors, which included their traditional beliefs, religious beliefs, health knowledge, socio-economic circumstances and their experience of the health systems remain invisible factors that contribute to their health decisions and choices. However, external factors such as the health views of their providers, tensions between the different health approaches and the community beliefs and practices, also contribute to health decisions and choices. These factors, coupled with the type of health condition experienced, create dilemmas in the participants' choice of what health approach to use and for what health condition. To attain healing, however, the study participants devised mechanisms to quell the tensions and complexities they face in their health-seeking journey and were able to navigate through the different available health approaches. These mechanisms included separating when they take the different treatments from the different health approaches, avoiding some treatments, or taking "weaker" "prescriptions" of some treatments.

While the participants in this study shared the 'standard' notion of progression on the cascade of HIV care, which begins from testing to viral suppression, they however, had different views on what is meant by 'efficient treatment' and 'healing'. For them, in contrast to the advice of biomedical HIV personnel, treatment and healing is not limited to the health services received within the clinic and hospital, nor is it about a choice of one health approach over another. For them, it involves the utilisation of 'other' healing and treatment regimens provided outside the

biomedical scope in order to ‘deal’ with aspects of their illness they find ‘untreatable’ or receive ‘insufficient’ treatment for within the biomedical space. For example, one of the participants, although a predominantly biomedical health user at the time of the study, asserted that while he feels he can only use the clinics for his HIV treatment and other related illnesses, he had in the past and was open to using other health systems for illnesses he believes can only be treated outside the biomedical space and only in the chosen health systems.

While PLHIV’s intentions for using plural health approaches is often seen as an attempt to treat or heal HIV, participants in this study, however, showed a variety of reasons as to why they make use of multiple health approaches. None of the participants had the intention of treating or healing HIV/AIDS using plural health care. In an instance where the participant appeared to be intending to treat HIV where he states that he uses traditional healing to cleanse his “dirty blood”, there is substantial reason to doubt the participant understands of HIV or his belief that he is infected with HIV. When attempts were made to gain his understanding of HIV, he said he was willing to engage in ART if he would not be asked to desist from using his traditional treatment by the nurses. This he said was because the traditional medicine had been helping him improve his health and he was still strong due to its use. Therefore, the mechanisms used allowed the participants to progress on the cascade of the HIV continuum while seeking the health services from plural health systems. The study shows that while PLHIV who are plural health users may face external factors in their health-seeking journey, they are not passive recipients of health; rather, they are active health users who, through the developed health-seeking mechanisms, express their agency and ability to choose their health services and systems towards attaining good health and health peace.

## CHAPTER SIX

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# APPENDICES

## APPENDIX 1.1: UKZN Ethical Clearance Letter



25 May 2016

Mr GG Darong (213571326)  
School of Social Sciences  
College of Humanities  
[darong@afriqcentre.ac.za](mailto:darong@afriqcentre.ac.za)

Protocol: Experiences of people living with HIV/AIDS in a plural Health Care System: probing tensions and complexities.

Degree: PhD

BREC reference number: BE005/16

The Biomedical Research Ethics Committee has considered and noted your application received on 14 January 2016.

The study was provisionally approved pending appropriate responses to queries raised. Your response received on 20 May 2016 to queries raised on 01 April 2016 have been noted and approved by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval.

This approval is valid for one year from 25 May 2016. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on 14 June 2016.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor Y Rambiritch  
Deputy Chair: Biomedical Research Ethics Committee

cc supervisor: [paiddoo@ukzn.ac.za](mailto:paiddoo@ukzn.ac.za)

Biomedical Research Ethics Committee  
Professor J Tsoka-Gwagweni (Chair)  
Westville Campus, Govan Mbeki Building  
Postal Address: Private Bag X64001, Durban 4000  
Telephone: +27 (0) 31 260 2499 Facsimile: +27 (0) 31 260 4819 Email: [bra@ukzn.ac.za](mailto:bra@ukzn.ac.za)  
Website: <http://research.ukzn.ac.za/Biomedical-Ethics/Biomedical-Research-Ethics.aspx>

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## APPENDIX 1.2: UKZN Ethical Clearance Letter: recertification



29 September 2017

Mr GG Darong (213571326)  
School of Social Sciences  
College of Humanities  
[darong@afriacentre.ac.za](mailto:darong@afriacentre.ac.za)

Protocol: Experiences of people living with HIV/AIDS in a plural Health Care System: probing tensions and complexities. Degree: PhD  
BREC reference number: BE005/16

### RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 25 May 2017  
Expiration of Ethical Approval: 24 May 2018

I wish to advise you that your application for Recertification received on 13 September 2017 for the above protocol has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

This approval will be ratified by a full Committee at its meeting taking place on 08 August 2017.

Yours sincerely

Mrs A Marimuthu  
Senior Administrator: Biomedical Research Ethics

cc supervisor: [nakhus@ukzn.ac.za](mailto:nakhus@ukzn.ac.za)

## APPENDIX 2.1: Letter of Collaboration from *The Bottlenecks'* Principal Investigator



Africa Centre for Health  
and Population Studies



Gabriel Gyang Darong,  
School of Social Sciences,  
University Of KwaZulu-Natal,  
Howard Campus  
Durban  
4041

22 October 2015

Dear Gabriel,  
Cc:

Supervisor 1: Dr. Maheshvari Naidu ([031-2607657/naiduu@ukzn.ac.za](mailto:031-2607657/naiduu@ukzn.ac.za))  
Supervisor 2: Dr Mosa Moshabela ([031-2601736/moshabela@ukzn.ac.za](mailto:031-2601736/moshabela@ukzn.ac.za))  
Research Office: Ms P Ximba ([031-2603587/ximbap@ukzn.ac.za](mailto:031-2603587/ximbap@ukzn.ac.za))

### **RE: PERMISSION TO CONDUCT RESEARCH**

This letter serves to confirm that I, Professor Vicky Hosegood, the Chief Principal Investigator of the Health Care Bottlenecks Study based at the Africa Centre for Health and Population Studies Mtubatuba, hereby acknowledge and approve the research of Gabriel Gyang Darong, titled: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**, within the Africa Centre for the completion of his Doctoral degree.

The researcher will:

- 1- Recruit participants for his study, whereby a copy of his study's information sheet will be presented to people living with HIV whom we identify as users of plural health care system and treatments.
- 2- Have access to the services of a psychologist and medical doctor to whom his research participants may be referred to when a need arises for them to consult either of the two professionals.
- 3- Have access to trained isiZulu-speaking fieldworkers and translators from the Africa Centre with vast experience in qualitative studies around uMkanyakude District.

Sincerely,

A handwritten signature in black ink, appearing to read 'Vicky Hosegood'.

Professor Vicky Hosegood  
Dept of Social Statistics and Demography  
University of Southampton / Africa Centre for Population Health  
[v.hosegood@soton.ac.uk](mailto:v.hosegood@soton.ac.uk)  
Postal: PO Box 198, Mtubatuba 3935,  
South Africa Physical: Africa Centre,  
R618 en route to Hlabisa, Somkhele  
Tel.: +27 (0)35 550 7500 Fax: +27 (0)35 550 7565  
Email: [info@afriacentre.ac.za](mailto:info@afriacentre.ac.za) Web: [www.afriacentre.com](http://www.afriacentre.com)

wellcome trust

## APPENDIX 2.2: CAB approval letter



27<sup>th</sup> August 2015

Human and Social Sciences Ethics Committee  
University Of KwaZulu-Natal  
Private Bag x7  
Congella 4013

Dear Sir/Madam

**Project title:** Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities

This serves to advise that the above-mentioned study was presented in detail to the Africa Centre Community Advisory Board (CAB) on 27<sup>th</sup> July 2015.

The CAB members asked questions about a wide range of aspects relating to the study. The questions and comments were adequately addressed by the study presenter, Gabriel Darong. The CAB members carefully considered the benefits of the study to individual participants and the community as whole. They supported the study and gave permission that the study is very good for the community of uMkhanyakude.

It is from this premise that the CAB hereby unconditionally grants permission to Gabriel Gyang Darong of the Africa Centre for Health & Population Studies and PhD student at the University of KwaZulu-Natal to conduct the proposed study, which will involve the recruitment of people living with HIV, faith/spiritual healers, traditional healers and clinicians.

Yours sincerely

**CAB Chairperson**

Rev SK Zulu

**CAB Secretary**

Ms Lungile Ngubane

---

Community Advisory Board Management Committee: SK Zulu, S Sithole, Lungile Ngubane, Sandile Mthethwa, Sindiswa Mthethwa

Postal: PO Box 198, Mtubatuba 2925, South Africa Physical: Africa Centre, R618 en route to Hlabisa, Sankhale  
Tel: +27 (0)35 560 7500 Fax: +27 (0)35 560 7565 E-mail: info@afriacentre.ac.za  
Website: [www.afriacentre.ac.za](http://www.afriacentre.ac.za)

## APPENDIX 3.1: The Department of Health's Consent Letter: Hlabisa Management's approval



Department  
Health  
PROVINCE OF KWAZULU-NATAL

HLABISA DISTRICT HOSPITAL

Physical Address: 50 Saunders Street, HLABISA 3937  
Postal Address: Private Bag X 3001 HLABISA 3907  
Tel: 035 838752 Fax: 035 838 1117 Email: martin.tshipuk@kzndoh.gov.za  
www.kzndoh.gov.za

**16 March 2016**

### **Permission to Conduct Research**

Dear Mr. SR Dlamini

The Hlabisa Hospital Research Committee has reviewed the proposal entitled: **"Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities"** and has granted permission for the study to proceed at Hlabisa Hospital.

Please note the following:

1. Please ensure that the conduct of the study is in line with the stipulations of the KZN Health Act of 2009 and the National Health Act (Act 61 of 2003).
2. Hlabisa Hospital has the right to withdraw this permission at any time as per the conditions of the Memorandum of Agreement between the Africa Centre and the KZN Department of Health.
3. This research may only commence once the UKZN Biomedical Research Ethics Committee or other registered Institutional Review Board has granted the study full approval.
4. Final approval must be granted by the KZN Health Research and Knowledge Management Unit
5. The researchers must communicate the findings of the research to this committee before publication.
6. Any Hlabisa Hospital resource required to conduct this study including staff time be declared up front before commencement of the research for the consideration of the Hospital Management Team.
7. Please ensure that there shall be no distraction in the rendering of patients care and you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.

The following requirements for this study to proceed are noted:

- Access to Somkhele, Mtubatuba, KwaMaane, Ntondweni, Madwaleni, Esiyembeni Clinics and Hlabisa Hospital.
- Access to Mpukunyoni, Machilini and Gunjaneni Clinics to enable saturation of recruitment.
- Permission to recruit health care providers and patients using HIV and ART services in the above mentioned facilities, and to conduct interviews only for data collection purposes, as per UKZN Ethics approval.
- Informed consent will be obtained from participants prior to enrolment on the study.

Yours faithfully

Dr. Martin Tshipuk  
Medical Manager on behalf of Hlabisa Research Committee

## APPENDIX 3.2: The Department of Health's Consent Letter: uMkhanakude District's approval



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

Umkhanakude Health District Office  
Dr C H Vaughan Williams  
Medical Manager, Senior  
Private Bag X 026, Jozini 3969  
Tel: 035 5721327, Fax: 035 5721251  
Cell: 072 584 3472  
Email: hervey.williams@kznhealth.gov.za

**Reference :**

Enquiries : Dr CH Vaughan Williams  
Telephone : 035-5721327 Ext 114

20 August 2015

Dear Dr Lessells,

I have pleasure in informing you that permission has been granted to you by the District Office to conduct research on in this district, entitled:

**'Experiences of people living with HIV/AIDS in a plural health care system: probing tensions and complexities'**

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. The District Office will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the District Office.

Sincerely,

C H Vaughan Williams  
Family Physician, Umkhanakude Health District Office

uMnyango Wezempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

## APPENDIX 3.3: The Department of Health's Consent Letter: KwaZulu-Natal Provincial approval



**health**

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

Physical Address: 33C Langabalele Street, Pietermaritzburg  
Postal Address: Private Bag X9051  
Tel: 033 395 2805/ 3199/3123 Fax: 033 394 3782  
Email: [hrkm@kzhealth.gov.za](mailto:hrkm@kzhealth.gov.za)  
[www.kzhealth.gov.za](http://www.kzhealth.gov.za)

DIRECTORATE:

Health Research & Knowledge  
Management

HRKM Ref: 129/16  
NHRD Ref: KZ\_2015RP59\_9

Date: 17 May 2016

Dear Dr G. Darong  
UKZN Africa Centre for Population Studies

### Approval of research

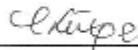
1. The research proposal titled '**Experiences of people living with HIV and AIDS in a plural health care system: probing tensions and complexities**' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at Hlabisa Hospital, Somkhole, Mtubatuba, KwaMsano, Ntondweni, Madwaleni, Esiyembeni, Mpukonyoni, Machibini and Gujaneni Clinic

2. You are requested to take note of the following:
  - a. Make the necessary arrangement with the identified facility before commencing with your research project.
  - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkm@kzhealth.gov.za](mailto:hrkm@kzhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

  
\_\_\_\_\_  
Dr E Lutge

Chairperson, Health Research Committee

Date: 19/05/16

Fighting Disease, Fighting Poverty, Giving Hope

**APPENDIX 4.1a: uMkhanyakude Head of Traditional Healers' approval  
(Original - isiZulu)**

ABELAPHI BASETHWANJANDE  
P.O. BOX 631  
HULHLWE  
39 60  
17 SEPTEMBER 2018

OziBik / Madam:

Sisikholile Sicelo Seno SizaSemulela. Kankulu

Inkinga esinako laPha emifusa ukwenza kama ukwamigo  
abelaphi baseMabuba bathi ikade kibeziwa ukwango  
bengacheli lutho. lokho kuzakwenza ukuthi ukwamigo lungachambi  
kakhulu abantu baseMabuba etukholeni kumbe nomo ulwazi  
koko beqala kanyalo.

Sizabonga:

District: Mkhanyakude : Chairperson: J. F. Mkhanyane  
Secretary: C. M. Mkhanyane

**APPENDIX 4.1b: uMkhanyakude Head of Traditional Healers' approval  
(Translated)**

**Appendix 4.1b: Gatekeeper Letter from the uMkhanaykude Head of  
Traditional Healers (Translated Version)**

Abelaphi Basemkhanyakude

P.O Box 631

Hluhluwe

3960

17 September 2015

Dear sir /Madam

We have received your request, and it will be great pleasure, we agree.

The challenge that we have is that where you want to conduct the research, the Traditional healers at Mtubatuba said that they have had about the research, but they never benefited anything. That will have a negative impact to the research, to not be successful as they are used for nothing; they are left without resources and information.

Thank you

District uMkhanyakude: Chairperson: JP Msezane

Secretary: CM Mathenjwa



**APPENDIX 4.2a: Mpukunyoni Head of Traditional Healers' approval (Original - isiZulu)**

Sanibong

Mina John Mbongiseni Mdletshe, usihlalo  
wabelaphi bendebuko eMpukunyoni  
Siynemukela nochwaniyo eniza nalo

Ozithobayo  
J.M. Mdletshe  
cell no: 073 4103750

JOHN Mdletshe

**APPENDIX 4.2b: Mpukunyoni Head of Traditional Healers' approval  
(Translated)**

Hello,

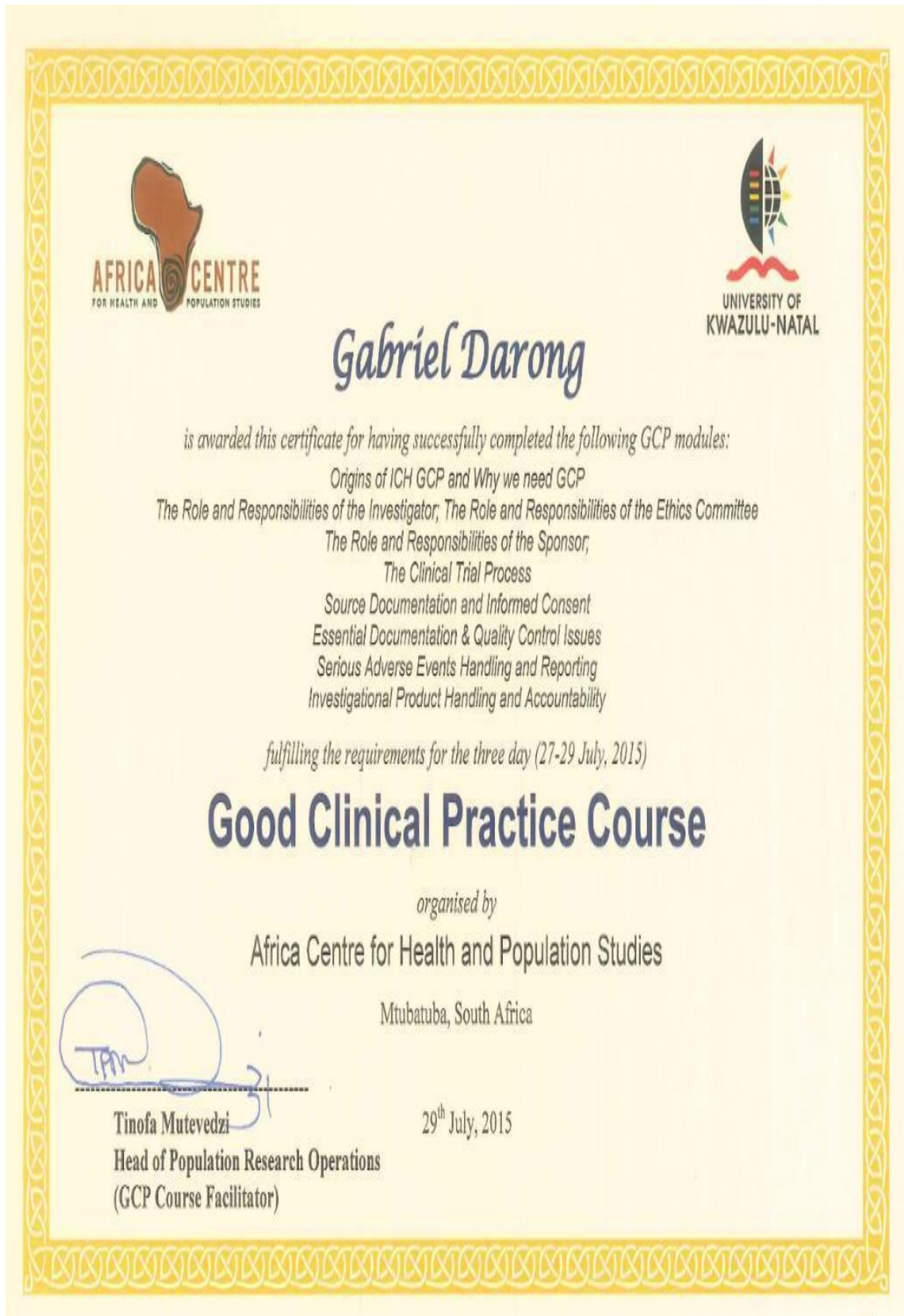
I John Mbongiseni Mdletshe, chair of the uMpukunyoni (Mtubatuba) Traditional Healers' welcome you and the research you will be conducting.

Sincerely,

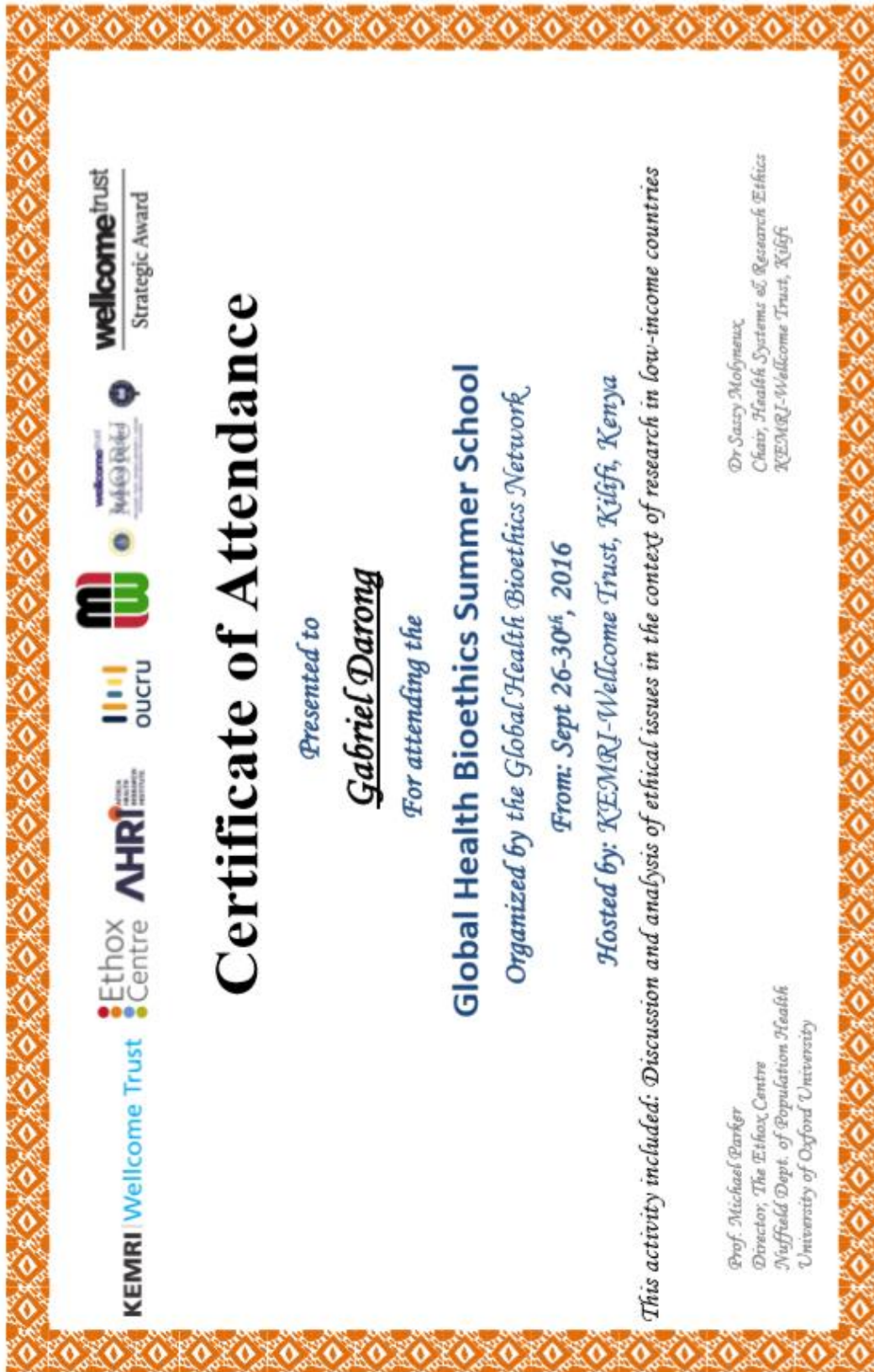
J.M Mdletshe.

Cell No: 0734103750

**APPENDIX 5.1: GCP certificate**



## APPENDIX 5.2: GHBN's 2016's Certificate



APPENDIX 5.3: GHBN’s 2017’s Certificate



## APPENDIX 6.1: Primary Participants' Information Form (English)



### Primary Participants' Information Form

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

Dear Respondent,

#### 1 Introduction

I, Gabriel Gyang Darong, a Doctoral student at the University of KwaZulu-Natal (student number 213571326), wishes to invite you to participate in a research project titled: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**. This is in requirement for my PhD in Anthropology. You have been chosen because you were identified and accepted to being a user of plural health services, as such, very relevant to this study. If you accept to participate in the study, you will be asked questions about your use different health systems and services.

#### 2 What is this study about?

This study seeks to understand the motivations behind the use of different health services by people living with HIV/AIDS, that is hospitals/clinics, traditional healers, and faith healers. The study will explore how you are able to negotiate the services you receive from these different health service providers. The study will also look at the role of the different health service providers in treating and reducing the spread of HIV/AIDS within their communities and how they understand the roles of other service providers carrying out similar activities.

#### 3 Who will take part in this study?

The study has two main groups of participants, primary and secondary. People living with HIV (PLHIV) are the primary focus while health care providers are the secondary participants. 20 PLHIV will be recruited and 30 health providers, doctors and nurses, traditional healers and faith/spiritual healers will be recruited from different facilities and their host communities uMkanyakude District. However, none of what you or any other participant shares, your or their identity will be disclosed to fellow participants or anyone and linked to you or them. Pseudonyms will always be used in referring to all participants.

#### 4 What will it mean to take part in the study?

If you agree to participate in the study, I will visit you on several occasions just for familiarity and later interview you on at 3 occasions with a possibility of more when really needed and with your willingness within the next ten months. These interviews will all be informal and semi-structured and will each last for 45 minutes but can be more or less, depending on your availability and willingness. These will be held at your home or any other location of your choice and comfort. Your participation in this study is voluntary. You may choose to withdraw from participating from the study at any point or choose not to answer any question that you do not feel comfortable answering and no penalty will be attached to any of such actions. The information that will be gathered from this study will be used in my thesis writing, academic journals and presented orally. However, your identity will be



protected at all times and will only be made known if you so wish. In order to protect your identity, when names are needed, a pseudonym will always be used.

#### 5 Is there any risk being in the study?

There are no major risks for being in the study as it only involves verbal interviews where questions related to your health-seeking behaviours will be asked. No emotionally evoking question will be asked during the interviews, however, if you find any question troubling or you become too exhausted to carry on with the interview, you may choose not to answer the question, postpone the interview or withdraw from the study without any negative repercussion for their withdrawal. In such moments you will also have the option of seeing a professional psychologist or medical doctor if a need arises for you to see either of them as they will be available to you. Your HIV status will be known to the interviewer who will be assisting in conducting the interview; however, your status and name will be kept anonymous through the use of pseudonyms throughout the data collection, write up of thesis and subsequent possible publications of the research findings. You may at some point use your funds for transportation for interviews at the Africa Centre, if you wish not to be interviewed at home; however, you will be reimbursed with R60, or more, depending on how much you would have spent, to cover for the used funds

#### 6 What are the benefits to being in the study?

Unfortunately, I will not be able to afford you any payment for your participating in this study; however, you will be reimbursed with R60 if you use your funds for transportation to any of the interviews. Refreshments will be provided after each interview to assist you replenish spent energy during each interview.

Sharing your experience of using plural health care system will allow us to understand how you are able to negotiate the health services you seek and receive from the different health providers you visit. It will also enable us to understand some of the benefits in each health system and how they contribute to your health life, or the barriers entrenched in each system's view of itself and the other and how such barriers contribute to creating division of loyalty amongst PLHIV, which in the end can endanger your healing process. In the end, the study will assist policy makers to create policies that speak to the plural usage of health services by PLHIV and create knowledge on how you are able to carry out this usage and your motivations for such. I hope you will take the time to participate.



**7 Who to contact if you want to know more, or if you have a problem at any time?**

If you have any questions or concerns about participating in this study, you may contact the researcher, his supervisors, or the University's research office through the contacts listed below.

Yours Sincerely,  
Gabriel Gyang Darong

Investigator's Signature \_\_\_\_\_ Date \_\_\_\_\_

**Interviewer:**

**Researcher:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Supervisor 1:** Prof. Maheshvari Naidu (031-2607657/ [naiduu@ukzn.ac.za](mailto:naiduu@ukzn.ac.za))

**Supervisor 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

**Research Office:** BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

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KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2602486 - Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

Or

Ms P. Ximba (031-2603587/ [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za))



## APPENDIX 6.2: Primary Participants' Information Form (isiZulu)



Iphhepha lohvazi nelichaza ngocwaningo

UNIVERSITY OF KWAZULU-NATAL  
SCHOOL OF SOCIAL SCIENCES

Mbambiqhaza,

### 1 Isingeniso

Mina, Gabriel Gyang Darong, umfundi wezobudokotela eNyuvesi yaKwaZulu-Natal, inombolo yomfundi 213571326, ngifisa ukukumema ukuthi ube yingxenywe yocwaningo, olusihloko sithi: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities.** Loku kuyingxenywe yesinye sezidingo sezifundo zami eziqinini zobudokotela ze-Anthropology. Ukhethwe emva kokuhlonzwa nokuzivumela ukuthi usebenzisa izinhlaka ezahlukene zezempilo, ngalokho ulufanele lolucwaningo. Abanye ababambe iqhaza kulolucwaningo bambandakanya abelaphi bendabuko, abahlengikazi, odokotela nabathandazi. Uma uvuma ukuba yingxenywe yocwaningo, uzobuzwa imibuzo mayelana nokusebenzisa kwakho izinhlaka ezihlukene zezempilo nezinsiza.

### 2 Lumayelana nani lolucwaningo?

Lolucwaningo lufuna ukuqonda izizathu ezenza abantu abaphila negciwane lesandulela ngculazi ukuthi basebenzise izinhlaka zezempilo nezindlela zokwelashwa ezihlukene, kusukela kwezokulapha zasentshonalanga, abelaphi bendabuko, nabathandazi, uhlobo lwezinsiza abazitholayo, nokuthi bazisebenzisa kanjani izinhlobonhlobo zemithi nezinsiza abatholayo. Lolucwaningo lizobheka ukuthi bakwazi kanjani ukusebenzisa izinhlobonhlobo zabahlinzeki bezinsiza ekwelapheni nasekunciphiseni ukwanda kwegciwane lengculaza neSandulela ngculazi emiphakathini yabo futhi nokuthi bawaqonda kanjani amaqhaza abanjwe ngabanye abahlinzeki bezinsiza abenza imisebenzi efanayo.

### 3 Ngubani ongaba yingxenywe kulolucwaningo?

Ucwaningo linamaqembu amabili abambambiqhaza, abokuqala nabesibili. Abantu abaphila negciwane lesandulela ngculazi ibona abazoba ngabokuqala ucwaningo elizogxila kubo bese kuthi abahlinzeki ngezinsiza zempilo bona ababambiqhaza besibili. Abantu abaphila negciwane lesandulela ngculazi abangamashumi amabili 20 bazokhethwa kanye nabahlinzeki bezempilo abangamashumi amathathu 30, okubala odokotela, abahlengikazi, abalaphi beNdabuko nabathandazi bazokhethwa ezinhlakeni ezahlukene emiphakathini yabo esifundeni saseMkhanyakude. Kodwa-ke, angeke sadahula enikucobelela nathi noma imininingwane yenu kwabanye ababambiqhaza.

#### 4 Kuyobe kusho ukuthini ukubamba iqhaza kulolucwaningo?

Uma uvuma ukuba yingxenywe yalolucwaningo, ngizokuvakashela kaningana ukuze sizojwayelana bese kuthi kamunwa sengizokubona okwesithathu sizoxoxisana mhlawumbe kunokwenzeka ukuthi siphinde sikhulume futhi uma kunesidingo futhi uma uthanda sizoxoxa nawe phakathi kwezinyanga eziyishumi ezilandelayo. Zonke lezizingxoxo zethu zobe zingenamcibilikisho futhi zivulelekile, futhi iyinye izothatha imizuzu engaphansi kuka45 kodwa kungaba ngaphezulu noma ngaphansi, kuzoya ngokuthanda kwakho nanokuthi uyatholakala yini. Lezingxoxo zizobanjelwa ekhaya lakho noma endaweni ozozikhethela yona lapho okhuhleke khona. Ukungenela kwakho lolucwaningo kungokuzikhethela. Ungakhethe ukuhoxa ekubeni yingxenywe yocwaningo noma ngayinini noma ukhetho ukungaphenduli imibuzo ongakhuhlekanga ukuyiphendula futhi akukho mhlawulo ozoyikhokha ekwenzeni njalo. Ulwazi elizoqoqwa kulolucwaningo lizosetshenziswa ezivivinyweni zami futhi kungenzeka lushicilelwe ephaphabhukwini luphinde lwethulwe ngomlomo. Yize kunjalo kodwa imininigwane yakho iyohlale iyimfihlo, iyokhishwa kuphela uma kuyisifiso sakho.

#### 5 Kungabe bukhona yini ubungozi kulolucwaningo?

Abukho ubungozi obungako ekubeni yingxenywe yalolucwaningo njengoba kubandakanya okukhulunywa ngomlomo lapho kubuzwa khona imibuzo emayelana nokufuna kwakho usizo lwezempilo. Ayikho imibuzo ephathana kabi emoyeni ngenkathi kuxoxwa, kodwa-ke, uma kukhona umbuzo okunika inkinga noma ufikelwa ukukhathala ekuqhubekeni nengxoxo, ungakhetha ukungawuphenduli umbuzo, uhlehlise ingxoxo noma uhowe ocwaningweni ngaphandle kwenkinga. emizuzwini ekanjena ungakwazi ukubonana nodokotela wezengqondo noma wezempilo uma kuvela isidingo ngesikhathi sisaxoxisana bazobe betholakala. Isimo sakho ngokwegciwane lesandulela ngculazi sizokwaziwa yilo ozobe ekubuzwa imibuzo nozobe elekelela engxoxweni enizoba nayo, kodwa, isimo sakho sempilo negama lakho lizogcinwa liyimfihlo kusetshenziswa ikhodi ekuqoqweni kolwazi, nasekubhalweni kwezivivinyo nakokunye okutholakele ocwaningweni okuzoshicilelwa. Kwesinye isikhathi kungenzeka usebenzisa imali yakho ukuze ugibele uze e-Africa Centre ukuzoxoxa nathi, uma ungathandi ukuvakashelwa ekhaya; kodwa-ke, uzonxeshelwa ngamarandi angamashumi ayisithupha R.60, noma ngaphezulu, koya ngokuthi usebenzisa imali engakanani, ukukhokhela imali oyisebenzisile.

#### 6 Iziphi izinzuzo ekubeni yingxenywe yalolucwaningo?

Ngeshwa, angeke ngibe namandla okukhokhela ngokubamba iqhaza kulolucwaningo ngakho akuzukuba namvuzo oyimali; kodwa, uzonxeshelwa ngamarandi angamashumi ayisithupha R.60 uma usebenzisa imali yakho ukugibela uze kunoma ngayiziphi izingxoxo. sizobe sikhulizekele ngokokubamba umoya kwingxoxo ngayinye ukubuyisa umdlandla emva kokuthi sikhulume nawe isikhathi sizoxe.

ukucobelelana nathi ngodhule kukho ekusebenziseni izinhlaka zezempilo ezahlukene kuzosenza siqonde ukuthi ukwazi kanjani ukusebenzisa izinsiza zezempilo ozidingayo nozitholayo kwizinhlaka ezahlukene zabahlizeki bezempilo obavakashelayo. Futhi sizokwazi ukuqonda ezinye zezinzuzo kuhlaka lwezempilo ngalunye nokuthi bekusiza kanjani ekuphilweni kwakho, noma izinselelo ezizinzile ohlakeni lulunye ekuziboneni kwayo



futhi nabanye futhi lezizinsalelo ziholela ekutheni kube khona uqhekeko ekuthembekeni kwalabo abaphila negciwane lesandulela ngculazi, mhlawumpe ekugcineni okungakhubuza inqubo yabo yokwelashwa. Ekugcineni, ucwaningo uzolekelela ababenzi benqubo mgomo ekwenzeni inqubo mgomo ezikhuluma ngokusentshenziswa kwezinhlaka zezempilo ezihlukene ngabantu abaphila negciwane lesandulela ngculazi futhi ekusunguleni ulwazi ekutheni bakwazi kanjani ukusebenzisa lokhu futhi nezizathu zabo ngalokhu. Ngiyathemba uzothatha isikhathi ubambe iqhaza.

**7 Ngubani ongamthinta uma udinga ulwazi olunzulu, noma unenkinga noma ngasiphi isikhathi?**

Uma kukhona imibuzo noma okunye okungakucaceli ngalolucwaningo ungaxhumana umcwaningi, umphathi wakhe noma ihhovisi lokucwaninga laseNyuvesi ezinombolweni ezingezansi.

Yimina ozithobayo,  
Gabriel Gyang Darong

Ukusayina komhlaziyi \_\_\_\_\_ Usuku \_\_\_\_\_

Lomsakazi: \_\_\_\_\_

Umcwaningi: Gabriel Gyang Darong (0785863009/ [213571326@stun.ukzn.ac.za/](mailto:213571326@stun.ukzn.ac.za/)  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

Umphathi 1: Prof. Maheshvari Naidu (031-2607657/ [maidun@ukzn.ac.za](mailto:maidun@ukzn.ac.za))

Umphathi 2: Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

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Email: [BRREC@ukzn.ac.za](mailto:BRREC@ukzn.ac.za)

Or

Ms P. Ximba (031-2603587/ [ximban@ukzn.ac.za](mailto:ximban@ukzn.ac.za))

## APPENDIX 7.1: Primary Participants' Informed Consent Form (English)



### Primary Participants' Informed Consent Form (English)

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

I \_\_\_\_\_ (optional and may be replaced by initials) hereby declare that I am fully informed about the nature of the research titled: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**, by the researcher/interviewer.

Yes..... No.....

I have also been well informed about the role that I stand to play if I am to participate in this project, which is participating in some interviews with the researcher. I am also aware that participation is voluntary and I can choose to withdraw from the process at any stage without any consequences to my withdrawal.

Yes..... No.....

I am aware of the risks and benefits I may incur for participating in this study.

Yes..... No.....

I am aware that all information obtained from me in the course of this project will remain confidential and that my identity will be well guided in the case of any publication of the obtained information.

Yes..... No.....

-----  
Initials                      Signature                      Date                      Place

I \_\_\_\_\_ (interviewer) state that I have fully informed the above participant of the nature and purpose of the research and the demands involved in his/her participation. I also state that I will do all in my power to maintain confidentiality and anonymity of the participant as I fully keep to the ethical conduct requested of me as a fieldworker.

-----  
Signature                      Date                      Place

If you have any questions or concerns about participating in this study, you may contact the researcher, his supervisors, or the University's research office through the contacts listed below:

**Researcher:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Supervisor 1:** Prof. Maheshvari Naidu (031-2607657/ [naidum@ukzn.ac.za](mailto:naidum@ukzn.ac.za))

**Supervisor 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

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Or

Ms P. Ximba (031-2603587/ [ximboap@ukzn.ac.za](mailto:ximboap@ukzn.ac.za))

## APPENDIX 7.2: Primary Participants' Informed Consent Form (isiZulu)



### Iphepha lemvume

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

Mina \_\_\_\_\_ (kungaba yigama noma uhlamvu lokuqala lwegama) Ngiyaqinisekisa ukuthi umcwangingi ungichazele ngokwanele ngohlobo locwaningo olusihloko sithi: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities,**

Yebo..... Cha.....

Ngiphinde ngachazelwa ngendima engizoyidlala uma ngibamba iqhaza kulolucwaningo, okuwukubamba iqhaza ezinkulumweni-mpendulwano nomcwangingi. Ngiyazi futhi ukuthi ukubamba kwami iqhaza kungokuzikhethela futhi ngingakhetha ukuhova nanoma yinini ocwaningweni ngale komthelela ekuhoxeni kwami.

Yebo..... Cha.....

Ngiyazi ngobungozi nezinzuzo engingazithola ekubeni yingxenye kulolucwaningo.

Yebo..... Cha.....

Ngiyazi ukuthi lonke ulwazi oluzotholakala kimi kulolucwaningo luyogcinwa luyimfihlo nokuthi imininingwane yami izoqashelwa uma kwenzeka kushicilelwa ulwazi olutholakele.

Yebo..... Cha.....

Igama	Ukusayina	Usuku	Indawo
Mina _____			
(lomsakazi) ngiyaqinisekisa ukuthi ngimchazele ngokuphele lobambe iqhaza ngohlobo nenhloso ucwaningo nokulindelekile ngokubamba kwakhe iqhaza. Ngiyaqinisekisa futhi ukuthi ngizokwenza konke okusemandleni ami ukugcina lolulwazi nemininingwane yababambe iqhaza kuyimfihlo ngokulandela imigomo ebekelwe abaqoqa ulwazi.			

Ukusayina	Usuku	Indawo
-----------	-------	--------

Uma kukhona imibuzo noma okunye okungakucaceli ngalolucwaningo ungaxhumana umcwangingi, umphathi wakhe noma ihhovisi lokucwaninga laseNyurvesi ezinombolweni ezingezansi.

Umcwangingi: Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

Umphathi 1: Prof. Maheshvari Naidu (031-2607657/ [naiduu@ukzn.ac.za](mailto:naiduu@ukzn.ac.za))

Umphathi 2: Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

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Or

Ms P. Kimba (031-2603587/ [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za))

## APPENDIX 8.1: Primary Participants' Audio Consent Form (English)



### Primary Participants' Audio Recording Consent Form (English Version)

UNIVERSITY OF KWAZULU-NATAL  
SCHOOL OF SOCIAL SCIENCES

I \_\_\_\_\_ (optional and may be replaced by initials)  
hereby declare that I am fully informed about the nature of the research titled: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**, by the researcher/interviewer.

Yes..... No.....

I also agree that the interview process will be electronically recorded and all collected information will be kept with confidentiality and high security.

Yes..... No.....

Initials

Signature

Date

Place

I \_\_\_\_\_ (interviewer) state that I have fully informed the above participant of the nature and purpose of the research and the demands involved in his/her participation. I also state that I will do all in my power to maintain confidentiality and anonymity of the participant as I fully keep to the ethical conduct requested of me as a fieldworker.

Signature

Date

Place

**Researcher:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Supervisor 1:** Prof. Maheshvari Naidu (031-2607657/ [naiduu@ukzn.ac.za](mailto:naiduu@ukzn.ac.za))

**Supervisor 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

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Or

Ms P. Ximba (031-2603587/ [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za))

## APPENDIX 8.2: Primary Participants' Audio Consent Form (isiZulu)



### Primary Participants' Audio Recording Consent Form (Zulu Version)

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

Mina \_\_\_\_\_ (kungaba yigama noma uhlamvu lokuqala lwegama) Ngiyaqinisekisa ukuthi umcwangingi ungichazele ngokwanele ngohlobo locwaningo olusihloko sithi: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities.**

Yebo..... Cha.....

Ngiyavuma ukuthi inkulumo-mpendulwano iziqoswa nokuthi lonke ulwazi oluzoqoqwa luzogcinwa luyimfihlo futhi luphephile.

Yebo..... Cha.....

-----  
Igama                      Ukusayina                      Usuku                      Indawo

Mina \_\_\_\_\_ (lomsakazi) ngiyaqinisekisa ukuthi ngimchazele ngokuphele lobambe iqhaza ngohlobo nenhloso ucwaningo nokulindelekile ngokubamba kwakhe iqhaza. Ngiyaqinisekisa futhi ukuthi ngizokwenza konke okusemandleni ami ukugcina lolulwazi neminingwane yababambe iqhaza kuyimfihlo ngokulandela imigomo ebekelwe abaqoqa ulwazi.

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Ukusayina                      Usuku                      Indawo

**Umcwangingi:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/ [gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Umphathi 1:** Prof. Maheshvari Naidu (031-2607657/ [naiduu@ukzn.ac.za](mailto:naiduu@ukzn.ac.za))

**Umphathi 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

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## APPENDIX 9.1: Secondary Participants' Information Form (English)



### Secondary Participants' Information Form/Study Description (English Version)

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

Dear Respondent,

#### 1 Introduction

I, Gabriel Gyang Darong, a Doctoral student at the University of KwaZulu-Natal (student number 213571326), wishes to invite you to participate in a research project titled: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**. This is in requirement for my PhD in Anthropology. You have been chosen because you were identified as a provider of health care services, including people living with HIV/AIDS, as such, a relevant person to this study. If you accept to participate in the study, you will be asked questions about your treatment approach and how you relate that to people living with HIV/AIDS. You will also be asked questions about the existence and use different health systems and services by people living with HIV/AIDS.

#### 2 What is this study about?

This study seeks to primarily understand the motivations behind the use of different health services by people living with HIV/AIDS, that is hospitals/clinics, traditional healers, and faith healers. The study will explore how they are able to negotiate the health services they receive from the different health service providers they use. The study will also look at the role of the different health service providers in treating and reducing the spread of HIV/AIDS within their communities and how you understand the roles of other service providers carrying out similar activities.

#### 3 Who will take part in this study?

The study has two groups of participants, primary and secondary. People living with HIV (PLHIV) are the primary focus while health care providers are the secondary participants. 20 PLHIV will be recruited and 30 health providers, doctors and nurses, traditional healers and faith/spiritual healers will be recruited from different facilities and their host communities uMkanyakude District. However, none of what you or any other participant shares, your or their identity will be disclosed to fellow participants or anyone and linked to you or them. Pseudonyms will always be used in referring to all participants.

#### 4 What will it mean to take part in the study?

If you agree to participate in the study, you will be visited on several occasions just for familiarity and later be interviewed at least once with a possibility of more when really needed and with your willingness within the next ten months. I will be seeking to know what types of services you render to the people living with HIV/AIDS who visit you, what you consider as your role in curbing HIV/AIDS, and how you understand the role of other health service providers. The head of your organisation is aware of this study and has given



permission for it. Your participation in the study will not in any way affect your work. These interviews will all be informal and semi-structured and will each last for 45 minutes but can be more or less, depending on your availability and willingness. These will be held at your home or any other location of your choice and comfort. Your participating in this study is voluntary. You may choose to withdraw from participating from the study at any point or choose not to answer any question that you do not feel comfortable answering and no penalty will be attached to any of such actions. The information that will be gathered from this study will be used in my thesis writing, published in academic journals and presented orally. However, your identity will be protected at all times and will only be made known if you so wish. In order to protect your identity, when names are needed, a pseudonym will always be used.

Secondary to your participation in the study, I will wish that you assist me in informing your patients about the study and present them with an information form with my contact to contact me if they wish to be part of the study. You can still be a part of the study even if you do not wish to carry out this secondary level of participation.

#### **5 Is there any risk being in the study?**

There are no envisaged risks for being in the study as it only involves verbal interviews where questions related to your views towards medical pluralism and approach to your clients and patients who make use of plural health care system and services, will be asked. No emotionally evoking questions will be asked during the interviews, however, if you find any question troubling or you become too exhausted to carry on with the interview, you may choose not to answer the question, postpone the interview or withdraw from the study without any negative repercussion for your withdrawal. Your name will be kept anonymous through the use of pseudonyms throughout the data collection, write up of thesis and subsequent possible publications of the research findings. You may at some point use your funds for transportation for interviews at the Africa Centre if you wish not to be interviewed at home; however, you will be reimbursed with R60, or more, depending on how much you would have spent, to cover for the used funds.

#### **6 What are the benefits to being in the study?**

Unfortunately, I will not be able to afford you any payment for your participating in this study; however, you will be reimbursed with R60 if you use your funds for transportation to any of the interviews. Refreshments will be provided after each interview to assist you replenish some of the energy spent during the interview.

Your organization will benefit from the Action Research Programme that will be initiated from within the year, 2016, as collaboration from this study and an established study at the Africa Centre. This programme will create room for dialogue whereby traditional healers, biomedical practitioners, and faith healers will be brought together to discuss some of the differences between them and ways for better coexistence and possible collaboration.

The of health service providers about the existence and use of plural health care system and how they approach patients and clients who use plural health systems are vital. Your views will allow us to understand how you understand your role and the roles of other health service providers in curbing HIV and how such understandings shape patients use of plural health systems and services. It will also enable us to understand some of the benefits or barriers in



each health system and how they contribute to the patients' health life. In the end, the study will assist policy makers to create policies that speak to the plural usage of health services by PLHIV and create knowledge on how they are able to carry out this usage and their motivations for such. I hope you will take the time to participate.

## 7 Who to contact if you want to know more, or if you have a problem about the study

If you have any questions or concerns about participating in this study, you may contact the researcher, his supervisor, or the University's research office through the numbers listed below.

Yours Sincerely,  
Gabriel Gyang Darong

Investigator's Signature \_\_\_\_\_ Date \_\_\_\_\_

### Interviewer:

**Researcher:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za) / [gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Supervisor 1:** Prof. Maheshvari Naidu (031-2607657/ [naiduru@ukzn.ac.za](mailto:naiduru@ukzn.ac.za))

**Supervisor 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

### Research Office: BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

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Tel: 27 31 2602486 - Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

Or

Ms P. Ximba (031-2603587/ [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za))

## APPENDIX 9.2: Secondary Participants' Information Form (isiZulu)



**Iphepha lolwazi nelichaza ngocwaningo**

**UNIVERSITY OF KWAZULU-NATAL  
SCHOOL OF SOCIAL SCIENCES**

Mbambiqhaza,

### **1 Isingeniso**

Mina, Gabriel Gyang Darong, umfundi wezobudokotela eNyuvesi yaKwaZulu-Natal (inombolo yomfundi 213571326), ngifisa ukukumema ukuthi ube yingxenywe yocwaningo, ohusihloko sithi: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**. Loku kuyingxenywe yesinye sezidingo sezifundo zami eziqinini zobudokotela ze-Anthropology. Ukhethwe emva kokuhlonzwa nokuzivumela ukuthi ungumhlinzeki wezinsiza zempilo kubantu abaphila negciwane lesandulela ngculazi, ngalokho ulufanele lolucwaningo. Uma uvuma ukuba yingxenywe yocwaningo, uzobuzwa imibuzo mayelana nokusebenzisa kwakho izinhloko ezihlukene zezempilo nezinsiza.

### **2 Lumayelana nani lolucwaningo?**

Lolucwaningo lufuna ukuqonda izizathu ezenza abantu abaphila negciwane lesandulela ngculazi ukuthi basebenzise izinhloko zezempilo nezindlela zokwelashwa ezihlukene, kusukela kwezokulapha zasentshonalanga, abelaphi bendabuko, nabathandazi. Lolucwaningo lizobheka ukuthi bakwazi kanjani ukusebenzisa izinhlobonhlobo zezinsiza zempilo abazithola ezinhloko ezihlukene zabahlinzeki bezinsiza zempilo abazisebenzisayo. Lolucwaningo lizobheka ukuthi bakwazi kanjani ukusebenzisa izinhlobonhlobo zabahlinzeki bezinsiza ekwelapheni nasekunciphiseni ukwanda kwegciwane lengculazi neSandulela ngculazi emiphakathini yabo futhi nokuthi bawaqonda kanjani amaqhaza abanjwe ngabanye abahlinzeki bezinsiza abenza imisebenzi efanayo.

### **3 Ngubani ongaba yingxenywe kulolucwaningo?**

Ucwaningo linamaqembu amabili abambambiqhaza, abokuqala nabesibili. Abantu abaphila negciwane lesandulela ngculazi ibona abazoba ngabokuqala ucwaningo elizogxila kubo bese kuthi abahlinzeki ngezinsiza zempilo bona ababambiqhaza besibili. Abantu abaphila negciwane lesandulela ngculazi abangamashumi amabili 20 bazokhethwa kanye nabahlinzeki bezempilo abangamashumi amathathu 30, okubala odokotela, abahlengikazi, abalaphi beNdabuko nabathandazi bazokhethwa ezinhloko ezihlukene emiphakathini yabo esifundeni saseMkhanyakude. Kodwa-ke, angeke sadahula enikucobelela nathi noma imininingwane yenu kwabanye ababambiqhaza.

### **4 Kuyobe kusho ukuthini ukubamba iqhaza kulolucwaningo?**

Uma uvuma ukuba yingxenywe yalolucwaningo, ngizokuvakashela kaningana ukuze sizojwayelana bese kuthi kamumva sizoxoxa mhlawumbe kanye mhlawumbe kunokwenzeka ukuthi siphinde sikhuhume futhi uma kunesidingo futhi uma uthanda sizoxoxa nawe phakathi kwezinyanga eziyishumi ezilandelayo. Ngizobe ngafisa ukwazi ukuthi iziphi izinhlobo zezinsiza ozinikezela kubantu abaphila negciwane lesandulela ngculazi abakuvakashelayo, nokuthi iliphi iqhaza olibambile ukulwisana negciwane lesandulela ngculazi, futhi nokuthi uliqonda kanjani iqhaza elibanjwe ngabanye abahlinzeki bezinsiza zempilo. Umphathi

wenhlango yakho uyazi ngalolucwaningo futhi usinikezile imvumo. Ukubamba kwakho iqhaza kulolucwaningo angeke kwaba nomthelela omubi emsebenzini wakho. Zonke lezizingxoxo zethu zobe zingenamcibilikisho futhi zivulelekile, futhi iyinye izothatha imizuzu engaphansi kuka45 kodwa kungaba ngaphezulu noma ngaphansi, kuzoya ngokuthanda kwakho nanokuthi uyatholakala yini. Lezizingxoxo zizobanjelwa ekhaya lakho noma endaweni ozozikhethela yona lapho okhululeke khona. Ukungenela kwakho lolucwaningo kungokuzikhethela. Ungakhethe ukuhoxa ekubeni yingxenywe yocwaningo noma ngayinini noma ukhetha ukungaphenduli imibuzo ongakhululekanga ukuyiphendula futhi akukho nhlawulo ozoyikhokha ekwenzeni njalo. Ulwazi elizoqoqwa kulolucwaningo lizosetshenziswa ezivivinyweni zami futhi kungenzeka lushicilelwe ephaphabhukwini luphinde lwethulwe ngomlomo. Yize kunjalo kodwa imininigwane yakho iyohlale iyimfihlo, iyokhishwa kuphela uma kuyisifiso sakho.

Okwesibili ekubeni yingxenywe yakho kulolucwaningo, bengifisa ukuthi ungisize ekwaziseni iziquli zakho mayelana ngalolucwaningo futhi ubanikeze ifomu lolwazi elinemininigwane yami abangaxhumana nami kuyo uma bengifisa ukuba yingxenywe yocwaningo noma wena ungaphumeleli ekubeni ngumbambiqhaza kulengxenywe yesibili yokubamba iqhaza.

#### 5 Kungabe bukhona yini ubungozi kulolucwaningo?

Abukho ubungozi obungabakhona ekubeni yingxenywe yalolucwaningo njengoba kubandakanya okukhulunywa ngomlomo lapho kubuzwa khona imibuzo emayelana nemubono yakho ekusebenziseni ukwelashwa okwahlukene futhi nendlela owelapha ngayo amakhasimende akho neziguli abasebenzisa izinhlaka nezinsiza zezempilo ezahlukene. Ayikho imibuzo ephathana kabi emoyeni ngenkathi kuxoxwa, kodwa-ke, uma kukhona umbuzo okunika inkinga noma ufikelwa ukukhathala ekuqhubekeni nengxoxo, ungakhetha ukungawuphenduli umbuzo, uhlehlise ingxoxo noma uhoxe ocwaningweni ngaphandle kwenkinga. emizuzwini ekanjena ungakwazi ukubonana nodokotela wezengqondo noma wezempilo uma kuvela isidingo ngesikhathi sisaxoxisana bazobe betholakala. Isimo sakho ngokwegciwane lesandulela ngculazi sizokwaziwa yilo ozobe ekubuza imibuzo nozobe elekelele engxoxweni enizoba nayo; kodwa, isimo sakho sempilo negama lakho lizogcinwa liyimfihlo kusetshenziswa ikhodi ekuqoqweni kolwazi, nasekubhalweni kwezivivinyo nakokunye okutholakele ocwaningweni okuzoshicilelwa. Kwesinye isikhathi kungenzeka usebenzisa imali yakho ukuze ugibele uze e-Africa Centre ukuzoxoxa nathi, uma ungathandi ukuvakashelwa ekhaya; kodwa-ke, uzonxeshelwa ngamarandi angamashumi ayisithupha R60, noma ngaphezulu, koya ngokuthi usebenzisa imali engakanani, ukukhokhela imali oyisebenzisile.

#### 6 Iziphi izinzuzo ekubeni yingxenywe yalolucwaningo?

Ngeshwa, angeke ngibe namandla okukhokhela ngokubamba iqhaza kulolucwaningo ngakho akuzukuba namvuzo oyimali; kodwa, uzonxeshelwa ngamarandi angamashumi ayisithupha R60 uma usebenzisa imali yakho ukugibela uze kunoma ngayiziphi izingxoxo. sizobe sikuhlinzekele ngokokubamba umoya kwingxoxo ngayinye ukubuyisa umdlandla emva kokuthi sikhulume nawe isikhathi sixose.

Inhlangano izozuza kwi Action Research Programme ezoqalwa kusukela ngo-April 2016 ezobe ibambisene ngalolucwaningo futhi nocwaningo olusungulwe e-Africa Centre. loluhlelo luzovula inkundla lapho koba khona nezingxoxo phakathi kwabalaphi beNdabuko nobezokwelapha ngokwaseNtshonalanga nabathandazi bazohlangukiswa ndawonye



ukudingida ukwehluka phakathi kwabo futhi nezindlela ezingcono zokuhlalisana futhi nokumbambisana okungabakhona.

ukucobelelana nathi ngodhule kukho ekusebenziseni izinhlaka zezempilo ezahlukeni nokuthi usebenzisana kanjani neziguli zakho namakhasimende abasebenzisa lezizinhlaka lokhu kuzosenza siqonde ukuthi ukuthi abahlinzeki bezinsiza zempilo ezahlukeni bawaqonda kanjani amaqhaza abawabambile futhi amaqhaza abanjwe ezinye izinhlaka zezempilo ekulweni nesandulela ngculazi futhi nokuthi lokhu kuqonda kukwakha kanjani ukusetshenziswa kwezinhlaka ezahlukeni nezinsiza izigulo. Futhi kuzosiza siqonde ukuthi ezinye zezinzuzo ohlakeni lwezempilo ngalunye nokuthi kunamthelela muni empilweni yeziguli, noma kunezinsalelo ezikhona ezidala uqhekeko ekuthembekeni phakathi kubantu abaphila negciwane lesandulela ngculazi, mhlawumpe ekugcineni okungakhubuza inqubo yabo yokwelashwa. Ekugcineni, ucwaningo uzolekelela ababenzi benqubo mgomo ekwenzeni inqubo mgomo ezikhuluma ngokusentshenziswa kwezinhlaka zezempilo ezihlukeni ngabantu abaphila negciwane lesandulela ngculazi futhi ekusunguleni ulwazi ekutheni bakwazi kanjani ukusebenzisa lokhu futhi nezizathu zabo ngalokhu. Ngiyathemba uzothatha isikhathi ubambe iqhaza.

#### 7 Ngubani ongamthinta uma udinga ulwazi olunzulu, noma unenkinga noma ngasiphi isikhathi?

Uma kukhona imibuzo noma okunye okungakucaceli ngalolucwaningo ungaxhumana umcwaningi, umphathi wakhe noma ihhovisi lokucwaninga laseNyuvesi ezinombolweni ezingezansi.

Yimina ozithobayo,  
Gabriel Gyang Darong

Ukusayina komhlaziyi \_\_\_\_\_ Usuku \_\_\_\_\_

Umsebenzi wocwaningo: \_\_\_\_\_

Umcwaningi: Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za/](mailto:213571326@stu.ukz.ac.za/)  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

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## APPENDIX 10.1: Secondary Participants' Informed Consent Form (English)



### Secondary Participants' Informed Consent Form (English version)

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

I \_\_\_\_\_ (optional and may be replaced by initials) hereby declare that I am fully informed about the nature of the research titled: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**, by the researcher/interviewer.

Yes..... No.....

I have also been well informed about the role that I stand to play if I am to participate in this project, which is participating in some interviews with the researcher/interviewer. I am also aware that participation is voluntary and I can choose to withdraw from the process at any stage without any consequences to my withdrawal. Yes..... No.....

I am aware that all information obtained from me in the course of this project will remain confidential and that my identity will be well guided in the case of any publication of the obtained information.

Yes..... No.....

I am aware of the risks and benefits I may incur for participating in this study.

Yes..... No.....

I agree..... /disagree..... to assist the researcher in recommending participants for the study.

-----  
Initials

-----  
Signature

-----  
Date

-----  
Place

I \_\_\_\_\_ (interviewer), state that I have fully informed the above participant of the nature and purpose of my research and the demands involved in his/her participation. I also state that I will do all in my power to maintain confidentiality and anonymity of the participant as I fully keep to the ethical conduct requested of me as a fieldworker.

-----  
Signature

-----  
Date

-----  
Place

If you have any questions or concerns about participating in this study, you may contact the researcher, his supervisor, or the University's research office through the numbers listed below.

**Researcher:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Supervisor 1:** Prof. Maheshvari Naidu (031-2607657/ [naiduni@ukzn.ac.za](mailto:naiduni@ukzn.ac.za))

**Supervisor 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

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Ms P. Ximba (031-2603587/ [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za))

## APPENDIX 10.2: Secondary Participants' Informed Consent Form (isiZulu)



### Iphepha lemvume (Zulu Version)

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

Mina \_\_\_\_\_ (kungaba yigama noma uhlamvu lokuqala lwegama) Ngiyaqinisekisa ukuthi umcwani ngichazele ngokwanele ngohlobo locwaningo olusihloko sithi: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities.**  
Yebo..... Cha.....

Ngiphinde ngachazelwa ngendima engizoyidlala uma ngibamba iqhaza kulolucwaningo, okuwukubamba iqhaza ezinkulumweni-mpendulwano nomcwani. Ngiyazi futhi ukuthi ukubamba kwami iqhaza kungokuzikhethela futhi ngingakhetha ukuboxa nanoma yini ocwaningweni ngale komthelela ekuhoveni kwami. Yebo..... Cha.....

Ngiyazi ukuthi lonke ulwazi oluzotholakala kimi kulolucwaningo huyogcinwa huyimfihlo nokuthi imininingwane yami izoqashelwa uma kwenzeka kushicilelwa ulwazi olutholakele. Yebo..... Cha.....

Ngiyazi ngobungozi nezinzuzo engingazithola ekubeni yingwenye kulolucwaningo. Yebo..... Cha.....

Ngiyavuma futhi ukuthi inkulumbo-mpendulwano iziqoswa nokuthi lonke ulwazi oluzoqoqwa luzogcinwa huyimfihlo futhi luphephile. Yebo..... Cha.....

Ngi-yavuma..... /yala..... ukusiza umcwani ukukhansa abazobamba iqhaza ocwaningweni.

-----  
Igama                      Ukusayina                      Usuku                      Indawo

Mina \_\_\_\_\_ (lomsakazi) ngiyaqinisekisa ukuthi ngimchazele ngokuphele lobambe iqhaza ngohlobo nenhloso yocwaningo lwami nokulindelekile ngokubamba kwakhe iqhaza. Ngiyaqinisekisa futhi ukuthi ngizokwenza konke okusemandleni ami ukugcina lolulwazi nemininingwane yababambe iqhaza kuyimfihlo ngokulandela imigomo ebekelwe abaqoqa ulwazi.

-----  
Ukusayina                      Usuku                      Indawo

Uma kukhona imibuzo noma okunye okungakucaceli ngalolucwaningo ungaxhumana umcwani, umphathi wakhe noma ihhovisi lokucwaninga laseNyuvesi ezinombolweni ezingezansi.



**Umcwaningi:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Umphathi 1:** Prof. Maheshvari Naidu (031-2607657/ [naidum@ukzn.ac.za](mailto:naidum@ukzn.ac.za))

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Or

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## APPENDIX 11.1: Secondary participants’ Audio Consent Form (English)



### Secondary Participants’ Audio Recording Consent Form (English Version)

#### UNIVERSITY OF KWAZULU-NATAL SCHOOL OF SOCIAL SCIENCES

I \_\_\_\_\_ (optional and may be replaced by initials) hereby declare that I am fully informed about the nature of the research titled: **Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities**, by the researcher/interviewer.

Yes..... No.....

I also agree that the interview process will be electronically recorded and all collected information will be kept with confidentiality and high security.

Yes..... No.....

Initials	Signature	Date	Place
_____	_____	_____	_____

I \_\_\_\_\_ (interviewer) state that I have fully informed the above participant of the nature and purpose of the research and the demands involved in his/her participation. I also state that I will do all in my power to maintain confidentiality and anonymity of the participant as I fully keep to the ethical conduct requested of me as a fieldworker.

_____	_____	_____
Signature	Date	Place

If you have any questions or concerns about participating in this study, you may contact the researcher, his supervisor, or the University’s research office through the numbers listed below.

**Researcher:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za)/  
[gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Supervisor 1:** Prof. Maheshvari Naidu (031-2607657/ [naiduu@ukzn.ac.za](mailto:naiduu@ukzn.ac.za))

**Supervisor 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

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Or

Ms P. Ximba (031-2603587/ [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za))

## APPENDIX 11.2: Secondary participants’ Audio Consent Form (isiZulu)



### Secondary Participants’ Audio Recording Consent Form (Zulu Version)

UNIVERSITY OF KWAZULU-NATAL  
SCHOOL OF SOCIAL SCIENCES

Mina \_\_\_\_\_ (kungaba yigama noma uhlamvu lokuqala lwegama)  
Ngiyaqinisekisa ukuthi umcwangingi ungichazele ngokwanele ngohlobo locwaningo olusihloko sithi:  
**Experiences of People Living with HIV/AIDS in a Plural Health Care System: probing tensions and complexities,**  
Yebo..... Cha.....

Ngiyavuma futhi ukuthi inkulumo-mpendulwano iziqoswa nokuthi lonke ulwazi oluzoqoqwa luzogcinwa luyimfihlo futhi luphephile.  
Yebo..... Cha.....

-----  
Igama                      Ukusayina                      Usuku                      Indawo

Mina \_\_\_\_\_ (lomsakazi) ngiyaqinisekisa ukuthi ngimchazele ngokuphele lobambe iqhaza ngohlobo nenhloso yocwaningo lwami nokulindelekile ngokubamba kwakhe iqhaza. Ngiyaqinisekisa futhi ukuthi ngizokwenza konke okusemandleni ami ukugcina lolulwazi neminingwane yababambe iqhaza kuyimfihlo ngokulandela imigomo ebekelwe abaqoqa ulwazi.

-----  
Ukusayina                      Usuku                      Indawo

Uma kukhona imibuzo noma okunye okungakucaceli ngalolucwaningo ungaxhumana umcwangingi, umphathi wakhe noma ihhovisi lokucwaninga laseNyuvesi ezinombolweni ezingezansi.

**Umcwangingi:** Gabriel Gyang Darong (0785863009/ [213571326@stu.ukz.ac.za](mailto:213571326@stu.ukz.ac.za) / [gdarong@afriacentre.ac.za](mailto:gdarong@afriacentre.ac.za))

**Umphathi 1:** Prof. Maheshvari Naidu (031-2607657/ [naiduu@ukzn.ac.za](mailto:naiduu@ukzn.ac.za))

**Umphathi 2:** Dr Mosa Moshabela (031-2601736/ [moshabela@ukzn.ac.za](mailto:moshabela@ukzn.ac.za))

**Ihhovisi locwaningo:** BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

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KwaZulu-Natal, SOUTH AFRICA  
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## APPENDIX 12: Skeletal Demography of Research Participants

Category of Participant	Pseudonyms	Gender	Age	Stage on the HIV Cascade	Formal Education Level	Employment Status	Profession	Number of Visits
Primary participants - PLHIV	Cothoza	Male	61	On-ART	Grade 9	Unemployed	N/A	Seven
	Mkhumbuleni	Male	61	On-ART	Tertiary level	Employed	Security Guard/Cashier	Six
	Mqondisi	Male	41	Off-ART	Grade 10	Self-Employed	Builder	Three
	Sifiso	Male	40	On-ART	None	Unemployed	N/A	Five
	Nobuhle	Female	23	On-ART	Tertiary	N/A	Student	Two
	Nikhil	Male	33	On-ART	Grade 9	Self-Employed	Traditional Healer	Three
	Lindiwe	Female	43	On-ART	Grade 11	Self-Employed	Business Woman/Traditional Healer	Three
	Nolwazi	Female	52	On-ART	Grade 4	Self-Employed	Traditional Healer	Three
	Nkosinathi	Male	28	Off-ART	Grade 11	Self-Employed	Traditional healer	Three

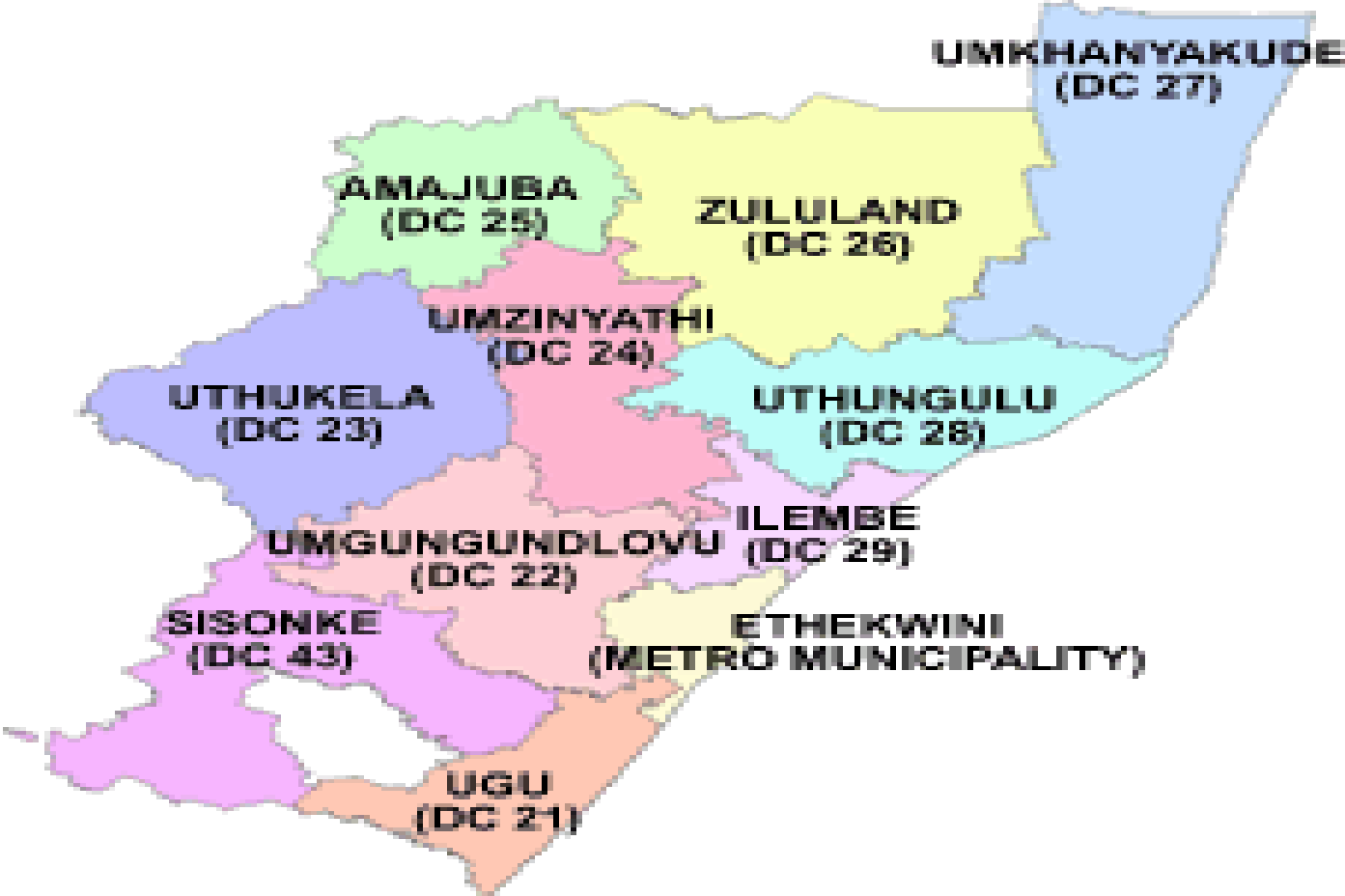
<b>Secondary Participants: Traditional Health Practitioners</b>	Mzwamandla	Male	41	N/A	Grade 12	Self-Employed	Traditional Healer	Two
	Velenkosini	Male	56	N/A	Grade 7	Self-Employed	Traditional Healer	Three
	Leonildo	Male	84	N/A	Grade 4	Self-Employed	Traditional Healer	Two
<b>Religious Leader</b>	Fundisa	Male	68	N/A	None	Employed	Religious/Church Leader	Three
<b>Biomedical Health Practitioners</b>	Thokozile	Female	46	N/A	Tertiary	Employed	Professional Nurse	Two
	Zanele	Female	41	N/A	Tertiary	Employed	Counsellor	Three
	Thokozile	Female	41	N/A	Tertiary	Employed	ART Nurse	Two
	Thobile	Female	46	N/A	Tertiary	Employed	Counsellor	Three
	Nikeziwe	Female	57	N/A	Tertiary	Employed	ART Nurse	Two

**APPENDIX 13: Map of South Africa**



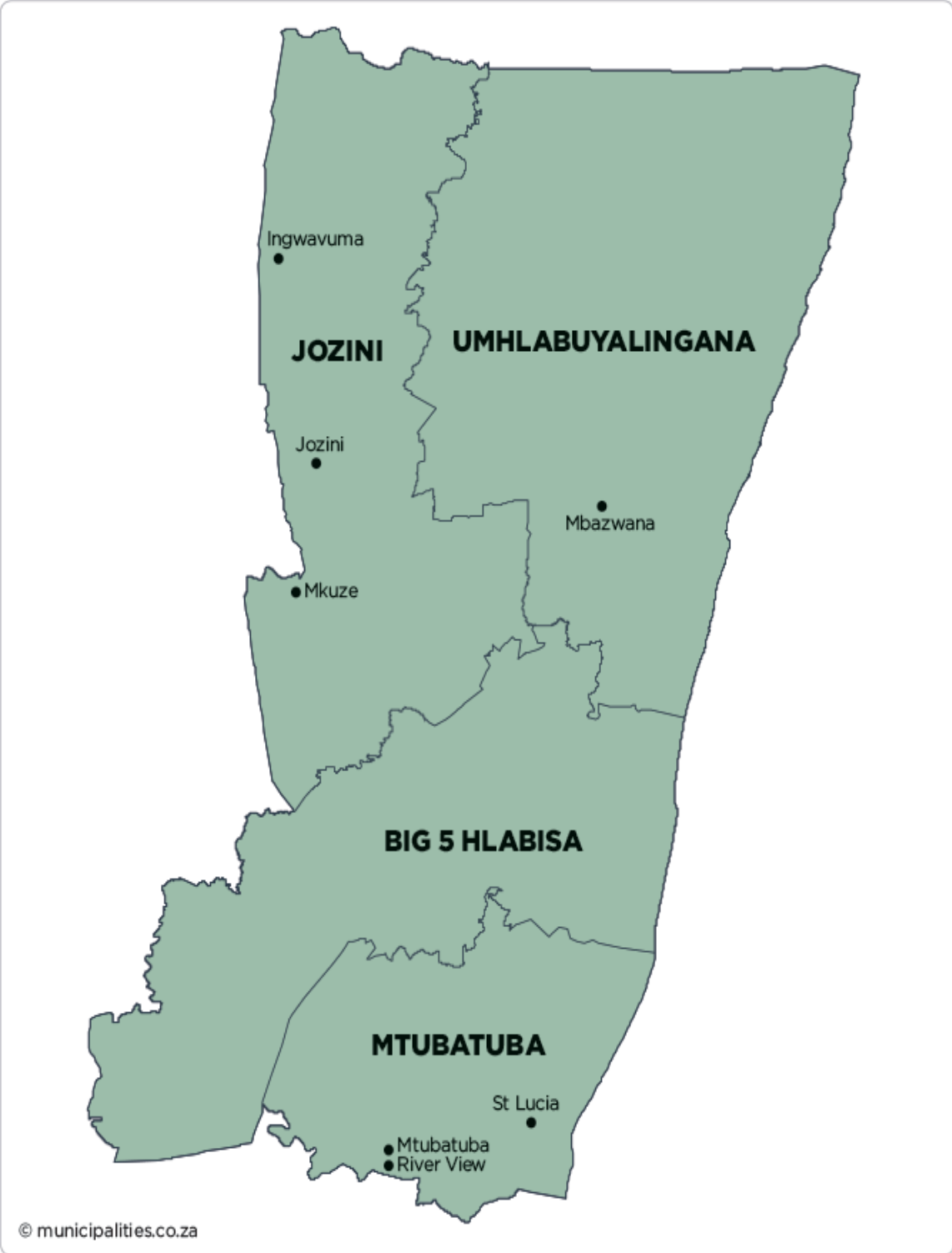
Source: SA Places (2018)

**APPENDIX 14: Map of KwaZulu-Natal**



Source: Trade & Investment KwaZulu-Natal (2018)

**APPENDIX 15: Map of uMkhanyakude District**



Source: Municipalities of South Africa 2018 (2018)



**APPENDIX 16: Front view of the Africa Health Research Institute - Mtubatuba Branch**



Photo taken by Vuyiswa Dlamini (2017)

**APPENDIX 17: A partial view of the study community: Rural homes**



Photo taken by Vuyiswa Dlamini (2017)

**APPENDIX 18: A partial view of the study community: Township homes**



Photo taken by Vuyiswa Dlamini (2017)

**APPENDIX 19: The study research assistant – in white attire – with some married women at a temple in the study community during a visit by the Shembe Nazareth Church leader – Unyazi**



Photo taken by Gabriel Gyang Darong (2017)

**APPENDIX 20: Married women at a temple in the study community during a visit by the Shembe Nazareth Church leader – Unyazi – dancing while others watched**



Photo taken by Samke Nxumalo (2017)

**APPENDIX 21: The study researcher and research assistant during a visit to a Shembe Nazareth temple in the study community**



Photo taken by an unidentified church member (2017)