The socio-cultural contexts of patients undergoing antiretroviral treatment in Petrusburg: an anthropological perspective

by

MOTSAATHEBE SEREKOANE

This thesis is submitted in accordance with the requirements for degree

Master of Arts

In the Faculty of the Humanities
(Department of Anthropology)

at the

University of the Free State

Supervisor: Prof. P.A. Erasmus
(Department of Anthropology, UFS)
Co-supervisor: Prof. HCJ van Rensburg
(Centre for Health Systems Research & Development, UFS)

MAY 2010

DECLARATION

I declare that the dissertation hereby handed for the qualification Master of Arts at the University of Free State, is my independent work and that I have not previously submitted the same work for a qualification at/in another university/faculty. I furthermore cede copyright of the dissertation in favour of the University of the Free State.

SEREKOANE MJ

BLOEMFONTEIN

May 2010

ACKNOWLEDGEMENTS

HIV/AIDS is a sensitive subject to talk about given the stigma and often aggravate handsful of painful emotions when people share their experiences. I owe my sincere gratitude to everyone who was involved this study:

- To my supervisor (Prof. P.A. Erasmus) and co-supervisor (Prof. Dingie van Rensburg). Their constant encouragement, scholarly advice, invaluable guidance, support, understanding and insightful contribution enable me to carry forward this work satisfactorily; and
- Staff and volunteers at Bophelong health care centre for making their facilities available.
- My colleagues, for their words of encouragement.
- My family, for all the prayers and words of encouragement.
- My God and ancestors for the wisdom, courage and strength.
- Pass my devotion, deep sense of gratitude and indebtedness to the informants who shared their deep and often painful information.

Special thanks to the financial assistance of the National Research Foundation (NRF) towards this research

ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ATTICC	AIDS Training, Information and Counselling Centre
ARV	Antiretroviral medicines/drugs
ART	Antiretroviral Treatment/Therapy
CBO	Community-based organisation
CHSR&D	Centre for Health System Research & Development
DoH	Department of Health
FBO	Faith-based organisation
HIV	Human Immune Virus
NAPWA	National Association of People Living with AIDS
NGO	Non-governmental organisation
NIP	National Intergrated Plan
PHC	Primary Health Care
PLWHA	People Living with HIV/AIDS
PLWHIV	People Living with HIV
RDP	Reconstruction and development programme
SM	Support mechanism
STI	Sexually transmitted infection
UFS	University of the Free State
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing

TABLE OF CONTENTS

PAGE NUMBERS

Acknowledgements i
Acronyms ii
List of figures vii
List of tables viii
Photos ix

CHAPTER 1: INTRODUCTION

1.1 Problem statement 1
1.2 Aims and objectives of the study 9

1.3 The research design 10
1.3.1 Literature study 10
1.3.2 Methods and techniques 11

1.3.3 Entering the field 15
1.3.3.1 Gatekeepers 15
1.3.3.2 Informants 15
1.3.3.3 Authorisation, ethical and confidentiality considerations 17
1.3.3.4 Advantages and disadvantages of indigenous anthropology 19

1.4 Research area and group 22
1.4.1 Research area 22
1.4.2 Research group/ biographical information 24
1.4.2.1 Informants' language distribution 25
1.4.2.2 Informants' age and gender 25
1.4.2.3 Informants' marital status, educational background, religious and social affiliation 31
1.4.2.4 Socio-economic conditions in the research area 33

1.4.3 Antiretroviral treatment 36
1.4.3.1 Treatment duration 36
1.4.3.2 ARV regimen complexity 38
1.4.3.3 ART related knowledge, attitudes and beliefs 38

1.5 Neighbourhood and health 39
1.5.1 Living conditions 40

1.6 Outline of the chapters 44

CHAPTER 2: ANTHROPOLOGICAL PERSPECTIVE ON THE STUDY OF HIV AND AIDS AND CLARIFICATION OF CONCEPTS

2.1 Introduction 45
2.2 The anthropological perspective 46
2.3 Explanatory model 49
2.4 Clarification of concepts/conceptualisation 54
2.4.1 Culture and society 54
2.4.2 Illness and disease 58
2.4.3 Sickness 63
2.4.4 Treatment management 65
2.4.5 Health care 67
2.4.6 Diagnosis 68
2.5 Reconciling professional and community interests 69
2.6 Conclusion 73

CHAPTER 3: CONTEXTUAL UNDERSTANDING OF ILLNESS AND HEALTH CARE

3.1 Introduction 74
3.2 Community and its social system 76

3.3 Aetiological views on HIV and AIDS 77
3.3.1 'Natural/unnatural' beliefs 79
3.3.2 Pollution beliefs 80
3.3.3 Agents or sources of illness 81
3.3.3.1 Ancestral spirits/ancestors 82
3.3.3.2 Witches 83
3.3.3.3 Supreme being 83

3.4 Sectors of health care 85
3.4.1 Popular (lay) health care 86
3.4.2 Folk and/or traditional health care 87
3.4.3 Professional/conventional health care 90

3.5 Complementary therapies/medicines 92
3.6 Adherence and non-adherence: clinical appointments and ART 95
3.6.1 Adherence to clinical appointments 97
3.6.2 Adherence to ARV treatment 98

3.7 Conclusion 108

CHAPTER 4: UNHEARED VOICES: EXPERIENCES OF PATIENTS ON ART AT PETRUSBURG

4.1 Introduction 111
4.2 Post HIV-positive test diagnosis 112
4.3 ARV treatment 114
4.4 Perceived challenges of adherence 120
4.4.1 Patients' socio-cultural contexts 120
4.4.1.1 Family social structure 121
4.4.1.2 Social stigma 124
4.4.1.3 Social support 129

4.4.1.4 Patients' social environment 130

4.4.2 Health care at Petrusburg 132
4.4.2.1 Availability of services 132
4.4.2.2 Poor doctor-patient communication 133
4.4.2.3 Access to health care 134
4.4.2.4 Conflicting cultural views 135
4.4.2.5 Complementary therapies 136

4.5 Perceived facilitators of ARV treatment adherence 140
4.5.1 Patients' socio-cultural contexts 142
4.5.1.1 Home-based care 142
4.5.1.2 Family 143
4.5.1.3 Friends/treatment buddy 143
4.5.1.4 Home-based carer 145

4.5.2 Disclosure 146
4.5.2.1 Reasons for disclosure 147
4.5.2.2 Consequences of disclosure 147

4.5.3 Routinisation 149
4.5.4 Patients' beliefs about treatment 149
4.6 Discussion 150

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS 162
LIST OF REFERENCES 170
SUMMARY/OPSOMMING 204
ADDENDUM
- Appendix A: Consent forms
- Appendix B: Interview Guides

LIST OF FIGURES

PAGE NUMBER

Figure 1: Informants' language distribution 25
Figure 2: Age of the informants 27
Figure 3: Informants' gender distribution 28
Figure 4: Informants' employment status 35
Figure 5: Informants' income status 36
Figure 6: Reconciling professional and community interests 72
Figure 7: Conceptual representation of the patient-by-treatment-context interactive framework 100

LIST OF TABLES

PAGE NUMBER

Table 1:	Population estimates and trends 1996-2001	24
Table 2:	Informants' marital status and educational background	32
Table 3:	Informants' religious affiliation	33
Table 4:	Informants' treatment duration	38
Table 5:	Key risk factors for non-adherence	107
Table 6:	Making headlines in a local medicinal market	139

PHOTOS

PAGE NUMBERS

Photo 1:	RDP house	41
Photo 2:	Streets	42
Photo 3:	Toilet facilities (bucket system)	43
Photo 4:	Emptying a used bucket	43
Photo 5:	Emptied bucket	43
Photo 6:	Dumping site	43

CHAPTER 1: INTRODUCTION

1.1 PROBLEM STATEMENT

Compared with other Southern African countries, South Africa is reported to have the highest prevalence of people infected with the human immunodeficiency virus (HIV) (Muula *et al*., 2007:2). Effective antiretroviral treatment (ART) is essential to increase patient survival (*cf.* Coetzee *et al*., 2004), improve quality of life (QoL) (*cf*. Mannheimer *et al.,* 2005; Wouters *et al*., 2007) and reduce mortality related to the acquired immune deficiency syndrome (AIDS) (*cf*. Cole *et al.,* 2003). For ART to be effective, the factors associated with treatment outcomes (positive or negative) need to be identified and addressed (*cf.* Kleinman *et al.,* 1978). Adherence[1] to antiretroviral treatment currently remains the only means by which people living with the human immunodeficiency virus (PLWHIV) and AIDS can not only enjoy a prolonged life but also a better quality of life (*cf*. Orrell, 2005:171-176; Orrell *et al.,* 2001:483-484; 2003:1369-1375). While richer countries in 1996 began using a combination of antiretroviral drugs to manage HIV effectively, this treatment was, for a considerable time, available only to a small minority of South Africans who could afford to pay for private health care

---

[1] In the recent literature the term *adherence* has come to be preferred to the term *compliance*, a term first used in the 1960s and one that has formed the basis of a professional discourse on the topic since the 1970s (Lerner, 1997:1423). *Compliance* has the "unfortunate connotation that the patient is docile and subservient to the provider" (Osterberg & Blaschke, 2005:487; Volmink & Garner, 1997:1403). According to Farmer (1997:349), the term *compliance* also "exaggerates patient agency, for it suggests that all patients possess the ability to comply or to refuse to comply with anti-HIV therapies". Therefore, the terms *adherence* and *non-adherence* - instead of *compliance* and *non-compliance* – as regards both medication and clinical appointments to describe patient behaviour will be used in this dissertation. In this study the word *adherence* will be used to refer not only to how closely the patients follow the prescribed treatment regimen, but also to the 'multifactoral process involving individual patient, the treatment regimen characteristics, and the quality of the patient-provider interaction' (Yun *et al*., 2005:432).

(Orrell *et al.,* 2001:485). While the work of non-governmental HIV[2] and AIDS[3] organisations and civil society groups in South Africa has been widely commended, government response has been severely criticised - both domestically and internationally. Many argue that the government's failure to act timeously and decisively has been linked to unorthodox attitudes regarding HIV and AIDS held by certain government officials. In particular, former President Thabo Mbeki has questioned scientific consensus on whether HIV causes AIDS, arguing that HIV is just one factor amongst many - alongside others such as poverty and poor nutrition - that might contribute to deaths resulting from immunodeficiency. The then, now late, Health Minister, Manto Tshabalala-Msimang continually promoted nutrition rather than antiretroviral drugs treatment as a means to manage HIV and AIDS, thereby earning herself a 'Dr Beet' name-tag[4]. Recently making media headlines was the statement made by current President Jacob Zuma during his rape trial in 2006, where he indicated that he

---

[2] HIV is transmitted, among others, through blood, semen and vaginal fluids. Once in the body, the virus uses the CD4 cells of the body's immune system to replicate itself, and in the process destroys these cells. These CD4 cells are vital in that they co-ordinate the body's immune system, while also protecting the human body from illness. As HIV in the body increases, the number of CD4 cells decreases, weakening the immune system even further.

[3] Acquired Immune Deficiency Syndrome (AIDS), on the other hand, is the collection of diseases that are acquired from HIV once the immune system is compromised or no longer able to protect the body from illness. As HIV weakens the immune system, a person with HIV develops diseases called *opportunistic infections*, which the body would normally be able to fight off. When the immune system has deteriorated to the extent that the person starts becoming ill with life-threatening and often unusual illnesses, the condition is called AIDS (Department of Health, 2003). AIDS is progressive - a disease of time. Once a certain density of symptoms is attained, the course of the illness can be swift, and brings terrible suffering. Besides the commonest presenting illnesses, a plethora of disabling, disfiguring, and humiliating symptoms causes an AIDS patient to become steadily more helpless and unable to control or take care of basic functions and needs (Sontag, 1983:107).

[4] This debate attracted the interest of the national and the international media, including websites, in particular www.tac.org.za, CNN, SABC news, e-tv, local and international newspapers.

took a shower after having sex with a woman who was HIV positive. The reason given was that the shower would minimise the risk of contracting HIV.

The above-mentioned situation has led many people to condemn South Africa's response to HIV and AIDS, including the Treatment Action Campaign (TAC), a community support organisation, then led by Zackie Achmat. The movement started in 1998 with the aim of putting pressure on the government to increase public access to ARVs[5]. Achmat, himself HIV positive, publicised[6] the situation by refusing to take ARVs until these were available to all South Africans. In 2003, TAC laid charges of culpable homicide against the then serving health minister, claiming that she was responsible for the deaths of many HIV-positive people in South Africa who had had no access to antiretroviral drugs.

In July 2002, the government, in partnership with TAC established a Joint Health and Treasury Task Team to, among other things, investigate issues relating to the financing of an enhanced response to HIV and AIDS within the framework of the Strategic Plan: Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment in South Africa (Joint Health & Treasury, 2003). A particular focus of the said task team was on the treatment, care and support of those infected with and affected by HIV and AIDS. At its August 2003 meeting, Cabinet received the report of the Joint Health and Treasury Task Team. As well

---

[5] It is a medical treatment using drugs that combat HIV rather than just the opportunistic symptoms of HIV. These drugs do not cure HIV but can, if successfully administered, slow down and even virtually stop the proliferation of HIV in the body. This reduces susceptibility to other diseases and allows not only longer, but also healthier life for those infected. In terms of South Africa public treatment protocol, these drugs are not prescribed until a patient's immune system cells (CD4 count) fall below 200. The goals of ARV treatment are to ensure maximum and lasting control of the amount of HIV in the body and durable suppression of viral load, to restore and preserve immunologic function, to reduce HIV-related illnesses and deaths; and in the long run, to improve the quality of life for people living with AIDS (Department of Health, 2003).

[6] Published on the TAC website, (www.tac.org.za)

as antiretroviral treatment, the report recommended comprehensive care, management and treatment (Department of Health, 2003).

As a result both of advances in the management of opportunistic infection and of the availability of antiretroviral treatments, individuals with HIV and AIDS have been, as stated, living longer and enjoying a better quality of life (*cf*. Orrell, 2005:171-176; Orrell *et al.,* 2001:483-484; 2003:1369-1375; Wouters *et al.,* 2007:1464-1466). Although antiretroviral treatment can prolong life, medication adherence also poses a challenge to HIV-infected individuals, because the success of the treatment regimes demands near perfect adherence to medication[7]. Thus, poor adherence will, in the longer term, threaten the sustainability of the ART programme. Poverty, stigma, traditional belief systems and non-disclosure have, among other things, been cited as posing a challenge to ARV treatment adherence (*cf*. Rintamaki *et al*., 2006:362-366; Roberts, 2000:157-166). Despite such challenges, South Africa is reported to have the highest levels of self-reported adherence to ARV treatment *(cf.* Orrell, 2005:171-176; Orrell *et al.,* 2001:483-484, 2003:1369-1375). While it might be easy to report adherence in a clinical setting, there are no easy answers regarding how to optimise adherence beyond/within the patient's socio-cultural context[8]. Being underscored by the complex interaction between the management of the regimen, the self and the environment, antiretroviral treatment adherence or non-adherence is complex in that it implies more than merely a patient's ability and motivation to be adherent.

---

[7] It is important to note that adherence influences both the effectiveness of ART (poorer adherence will result in worse treatment outcomes) and the costs of ART (poor adherence translate's into drug resistance, which would require people to be treated with more expensive drugs) (Jiang *et al.,* 2003:1004-1006; Reynolds *et al.,* 2004:146; Turner, 2002:147-148).

[8] The term *socio-cultural* in a health context refers to the actual living conditions - such as poverty, cultural values, norms, attitudes and worldview - that reflect a particular social and cultural context or 'whole person' (Cockerham, 1995:6).

Until recently, the bulk of research looking at ARV adherence/non-adherence has focused on the adherence barriers/challenges at the individual level (e.g. health beliefs, regimen complexity, medication side effect, forgetfulness, routinisation), with less emphasis on the many system-level factors (e.g. poverty, living conditions, social support, stigma, etc.) that potentially impact on patients' adherence behaviour (*cf.* Parker, 2001). Failure to address such system-level factors in research studies - especially within the patient's socio-cultural context - holds the potential to limit our understanding of precisely what treatment programme elements are critical towards ensuring the highest level of treatment adherence possible (*cf.* Kleinman *et al.,* 1978). This is especially true because biomedical science tends to 'blind' health professionals both to questions of illness and to different versions of clinical reality, which - though deemed a necessary part of health care - are nevertheless a non-biomedical aspect of clinical practice (Kleinman *et al*., 1978:256).

Plowden (2005:27) would have it that an important step in decreasing this disparity is to understand the socio-cultural factors that act as motivators and barriers to seeking care and, ultimately, adherence. Education, economy, religion, family/kinship, and politics interact to influence how an individual behaves (*cf*. De Reuck, 2008). In the case of men, these dimensions influence their perceived ability to seek care, which, in turn, impacts on their health behaviour. In particular, fatalism - defined by Plowden (2005:16) as the "surrendering of power to external forces of life which destroys personality, potential, hope and life", is deemed, especially in the case of men, to be a major barrier to seeking care and participating in any treatment roll-out. The latter is underscored by the manner of traditional men's development of role, values, world view, thoughts and behaviour.

While neither denying the contribution made by biomedical research nor the key importance of continuing with it, one nevertheless finds it regrettable that traditional biomedical research approaches that guide health care research are responsible for the neglect of a more holistic view of ARV treatment adherence. Some of the problems caused by such neglect are worth noting:

- The ingrained ethnocentrism and scientism dominating the modern medical professions (both in developed and developing societies) follow the paradigm of biomedical science that emphasises, in research, only those variables "compatible with biological reductionism and technological solutions", even if the problems are social ones. This bias excludes the significant contribution of social science inputs into medicine, especially at the clinical level (Kleinman, 1980:32; Kleinman, 1995:9). By freeing ourselves from ethnocentric and medicocentric views we may, according to Kleinman *et al.* (1978:251), begin to recognise important issues (socio-cultural context) that have thus far been systematically ignored.

- In Kleinman's (1980:32) view, the bias of many health professionals in developing societies is to restructure health care delivery in their countries by copying an idealised health care model of professional care in technologically advanced societies. This fictive view of health care does not correspond to the actual situation in developing societies. Here an estimated 70% to 90% of all self-recognised episodes of illness and sickness are managed exclusively outside the parameters of the formal health care system, namely in the family context (Abosede, 1984:699-70; Dean, 1981:673-687; Kleinman *et al.,* 1978:251). This bias prevents the development of a health care system that is sensitive to the socio-cultural realities of patients, in particular, their socio-political, economic and cultural concerns.

- Another problem in this respect concerns the long-standing tendency of both researchers and clinicians in biomedicine to investigate healing as if it were a totally independent, timeless, culture-free process to be understood as an isolated special case. They, according to Kleinman (1980:33), do not regard healing as a core function of health care systems to be studied on

> their own terms within specific social and cultural contexts. Instead, they make superficial reductive comparisons that obscure more than they reveal.

Contrary to the aforementioned approaches and assumptions, the view that this study advocates calls for the investigation and analysis of ARV treatment adherence in the same way that, for example, political systems, religious systems, language and other symbolic systems are studied, analysed and understood. The aforesaid elements of the socio-cultural context provide much of the specific content that characterises health care systems, and they therefore represent major determinants of the peculiar profile of a given system. For Kleinman (1980:33) it is obvious why it is necessary to study how the health care system relates to its socio-cultural context. Biomedical views/explanations of diseases played a part in the earliest conceptualisation of HIV and AIDS in African societies, yet more than 20 years have passed since then. Indigenous views about the illness complex have expanded and have frequently been rearranged in the intervening years. However, these transformations have been largely ignored by biomedical research and are little understood (Liddell *et al.,* 2005:695).

While Mabunda (2001:12-14) maintains that indigenous interpretations of ill health in communities have a long history, surprisingly little is known about how African societies initially constructed illness representation for HIV and AIDS (Liddell *et al*., 2005:695). The suppression of the potential role of indigenous attribution may, in the view of Liddell *et al*. (2005: 696), have been due both to the scale of the disease’s progression, and to the investment made by South Africa, with the help of United States Agency for International Development (USAID), and the World Health Organization (WHO) in promoting biomedical research, and towards the understanding and management of HIV and AIDS and ARV treatment. Despite the enormity of HIV and AIDS, it is questionable whether a single causal explanation could subvert a historical and responsive cosmology of illness that serves important societal and personal functions. Furthermore, in today’s multicultural South African society, assuring quality health care for all patients would decidedly require that health care workers understand how each patient's socio-cultural context affects his/her health beliefs and behaviours (Mabunda, 2001:12-14).

In South Africa, most black patients who consult a doctor, inevitably consult a doctor trained in western medicine, which implies that the encounter between them occurs in a cross-cultural context, because doctors and such patients often have different belief systems about the causes of illness or the frame of reference regarding health care. Having different belief systems/frames of reference, here means that doctors and their patients have different ideas about the causes, prognosis and treatment of the condition (De Villiers, 1991:69-72; *cf*. also Cockerham, 1995:176; Kleinman *et al.,* 1978:253-254; Kleinman, 1980:286-306; 1988:121-136).

Given the importance of proper patient-physician communication and understanding, and addressing socio-cultural factors in the medical encounter, anthropological and cross-cultural studies have developed clinical guidelines to address these issues (Kleinman *et al*., 1978:256), which are however not widely used in medical education (*cf*. Kleinman, 1995:9). Park *et al.* (2006:477), for example, maintain that central to the lack of endorsement of cross-cultural training in medical education are the generally associated views about the lack of usefulness of said guidelines for medical encounters. Reasons for this scepticism include, among other things, concerns that clinicians would be expected to know every detail about every culture and that they generally lack time, especially given the patient-doctor ratio. In contrast to these views, Kleinman (1980:xi-xiii) emphasises that the need to provide effective and inclusive quality health care to patients from differing cultures is becoming increasingly important for health care providers across health care sectors. In addition, Kleinman *et al.* (1978:252, 254, 256) and Helman (2000:143-144) reiterate that quality care must be socio-culturally sensitive to overcome the prevalence and challenges of treatment adherence in communities. In order to address such challenges, these authors suggest that health care workers should understand the diverse health practices in the communities they serve and also how these could potentially impact on treatment adherence.

Anthropological studies have shown that patients' explanatory models[9] are necessary additions to the treatment criteria used by health providers (Nanda & Warms, 2002:138; *cf.* Kleinman, 1980:104; 1988:121). Kleinman *et al*. (1978:251-258) introduced the concept of the explanatory model in applying anthropological insight into clinical practice. They maintain that, in the health care encounter, patients and practitioners may be working with different and competing models and that such a mismatch may lead to the kind of misunderstanding that results in either ineffective treatment or non-compliance (*cf.* Dyck, 1998:75).

This study argues that the above-mentioned indicators provide important information that can be used not only to identify causal reasoning, and an understanding of ill health and adherence to treatment, but also to assist health practitioners in ascertaining the most effective means of intervention within a particular society or community.

1.2 AIMS AND OBJECTIVES OF THE STUDY

Given the stated importance of proper adherence management, the aim of this study is to conduct an ethnographic inquiry into the nature and role of individuals' socio-cultural contexts on treatment adherence/non-adherence in respect of antiretroviral treatment. Specifically, this study wishes to:

---

[9] Explanatory models (e.g. perceptions and views on HIV and AIDS, on facilitators and barriers of adherence, information on gender differences, life experiences, social class, family networks and relationships, religious and culturally-patterned fears, as well as health beliefs) are defined by Kleinman (1980:189) as a useful way of looking at the process by which illness is patterned, interpreted and treated by both patients and health practitioners. These models are culturally shaped clusters of health beliefs and actions through which a person explains an illness and has his or her expectations of what can or should be done about it (*cf.* Dyck, 1998:75; Hardon *et al.*, 1995:13).

- Give an overview of the anthropological conceptualisation of and perspectives on the study of HIV and AIDS;
- Determine and interpret the research informants' HIV and AIDS explanatory models;
- Understand the cosmological assumptions that shape the informants' explanatory models, particularly those concerning the notions of cause and effect of ill health;
- Record and elicit the informants' illness narratives and experiences of HIV and AIDS, as well as ARV treatment; and
- Reflect on the socio-cultural contexts of the informants and determine the dominant factors that either facilitate or act as barriers to treatment adherence.

1.3 THE RESEARCH DESIGN

1.3.1 Literature study

Anthropological literature on health beliefs, health and illness behaviour, health-seeking behaviour, access to health care and treatment has informed this study, not only in respect of current empirical evidence on the topic, but also with regard to theoretical, conceptual and methodological issues. Arthur Kleinman, trained both in psychiatry and anthropology and also his research associates (Das, V., Lock, M. 1997; Eisenberg, M.D., Good, B. 1978; Seeman, D. 2000) were used as primary sources, because they have published widely on indigenous ethnomedicine, health-related beliefs and knowledge systems. Other related sources, especially Helman's revised versions (1990; 2000), broaden the scope of understanding through the inclusion of constructivist critics and the development of new ideologies. Given the scope of the research, the basic literature on the following four broad fields of enquiry was required:

- Literature describing methodology and techniques in the Humanities: anthropological and sociological literature - specifically Denzin and Lincoln (1994) and Bernard (1995) and also sources of a more general nature, such as Babbie and Mouton (2001), Le Compte and Schensuls (1999) and Hardon *et al.* (1995) were used;

- Literature concerning medical anthropology: the most important sources are those of Lieban (1973), Kleinman (1980; 1988), Helman (1990; 2000) and Hardon *et al*. (1995);

- Sources focusing on explanatory models: Kleinman (1980; 1988), Helman (1990; 2000) and Hardon *et al*. (1995) were consulted;

- Documentation pertaining to HIV, AIDS and ARV treatment: the government's Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment in South Africa (Department of Health [operational plan] 2003); Van Rensburg (2004); Wouters *et al*. (2007) and De Reuck (2008) were consulted.

1.3.2 Methods and techniques

This is an ethnographic study that follows a qualitative methodology based primarily on case studies[10]. Case studies are used, because I deliberately wanted to cover contextual conditions that are able to either facilitate or to hinder both clinical appointment and medication adherence, especially because the boundaries between self-reported adherence and the patient's socio-cultural context are not clearly evident. Based on this understanding, the use of qualitative research methods (specifically descriptive narratives) was primarily intended for the in-depth exploration of topics about which little was known or where what I wanted to know could only be uncovered with difficulty. Such topics

---

[10] A case study represents an intensive empirical inquiry of a single unit that investigates a contemporary phenomenon within its real-life context (Babbie & Mouton, 2001:280; Yin, 2003:12).

are, for example, the sensitivity surrounding being HIV positive and the emotional burden of being HIV positive and on ARV treatment, and also capturing the lived experiences from the perspectives of those who lived them and then to create meaning from them. What this entails is depicted by Babbie and Mouton (2001:270) as “an attempt to study human action from the perspective of the social actors themselves” (referred to by anthropologists as the *emic* or insider perspective). This approach was helpful in eliciting thoughts, memories and feelings in a private, safe and non-judgemental environment established by an empathetic interview.

Research using qualitative methods works with small samples of people, nested in their context and studied in depth (Daly *et al*., 1992:9; Power 1998:687-688). Qualitative samples tend to be purposive, rather than random. Bearing in mind the number of people living with HIV and AIDS who are making themselves available for participation in long-term research projects, possible suspicion and gossip by neighbours that might be triggered by the researcher’s frequent visits, the emotional burden of interviews, the highly sensitive nature of the disease, the frequent opportunistic and disabling infections, and the high casualty rate of the sample, a purposive sampling method was adopted. The sample for this study comprised eight (8) people living with HIV and AIDS, identified at the local Primary Health Care Clinic at Petrusburg.

Fieldwork was conducted during both the last six months of 2005 and the first six months of 2006, and was followed by discussion of the results with the informants in 2008[11]. The fieldwork-process involved the observation of the interactions of the informants within their respective contexts, and aimed to understand the influence of multilevel social systems on informants’ perspectives

---

[11] The aim of this last visit was to discuss the preliminary research findings with informants. This involved a consultative process with key informants. The feedback received was used to validate the research findings and to revisit and to ascertain that the inferences drawn and conclusions made were correct.

and behaviours. Triangulation, in particular participant observation[12], informants' narratives, focus-group interviews and life histories, were employed to improve data collection reliability and validity.

The advantage of using focus groups for this study was that these helped me not to discriminate against people who were unable to read or write; I could also encourage participation from those people reluctant to be interviewed on their own, or who felt that they had nothing to say or who were deemed unresponsive, but nevertheless could engage in the discussion generated by other group members.

Through participant observation I immersed myself in the lives of the locals. Relevant information was collected by means of informal visits paid to informants at their respective homes. These personal visits were aimed at sharing moments in the daily-life experiences of informants, such as taking pills, meeting in support groups for PLWHA, consultations at clinics, and other events that could deepen my understanding of how the patients' socio-cultural contexts often inseparably inform not only the daily activities, but also the choices to be made, in the context of HIV and AIDS care and ARV treatment.

Interviews followed the format of open-ended questions in a face-to-face, conversational style rather than a formal question-and-answer format. Probing

---

[12] Establishing a place at Petrusburg on a relatively long-term basis in order to investigate, experience and represent the social life of and the social process around that involve people living with HIV and on ARV treatment. According to Robert *et al.* (2001:352), ethnographers until recently restricted their interest in participant observation to such issues as the vagaries of establishing such a place, the need for emphatic immersion in the daily life and the meaning systems of informants, and the ethical and political issues arising from such efforts. But participant observation involves not only gaining access to and immersing oneself in new social worlds, but also producing written accounts and description that bring versions of these worlds to others. Geertz's (1973:19) early insistence on the centrality of inscription in ethnography, calling attention to the fact that the ethnographer inscribes/writes down social discourse, sparked growing recognition that the ethnographer is not only the scribe, but also the explorer and the quasi-insider of both the exotic and the familiar social world.

was used as and when required. The interviews were conducted in a private room or place over five sessions each lasting 60-90 minutes. Information gathered during the interviews was immediately transcribed from field notes. The transcripts were scrutinised to provide an understanding of the process, the links and the various themes. When there was inadequate information or when clarification was needed, a note was made on the transcripts and clarified with the informant in a subsequent session, thus making data analysis a continuous process.

All interviews were facilitated by the researcher accompanied by the local home-based carer. The latter helped with the location of informants' homes and with translation as the need arose. It is common practice among anthropologists to establish rapport between gatekeepers and informants. This is especially necessary when dealing with a secretive and not easily discussable topic such as HIV and AIDS. It was deemed necessary to meet with informants to build a relaxed and trusting working relationship.

As a researcher, I took into account the emic perspective, which assumes that there is no *one* correct view. This is a helpful premise when one is considering the thoughts and opinions of informants, first singly and then collectively. This approach allows one to make a nuanced interpretation of what has been reported by a wide variety of informants.

The *emic perspective* describes what things mean to the members of a society. Emic measures focus on local and idiosyncratic content. In this context, the emic assessments provided a qualitative description of the idiosyncratic meaning ascribed to adherence. To understand the cultural context of health problems as it relates to adherence to ART at Petrusburg, it is essential to work with this key concept. Emic perspectives are useful for examining when we are seeing things from our own point of view and when we are trying to understand someone else's view of things. The emic perspective reveals the meaning that people attach to things from their own cultural perspective.

Although editing of sorts occurred in the transcription of field notes, it is hoped that the final product is representative of the views of the informants of this research. A method linking the individual experiences of informants with a broad level of analysis that includes global factors that play themselves out on both a local and an individual level is central to this study. It is, as Kleinman *et al.* (1997:x) note, impossible to separate the individual from a social level of analysis, health from social problems, and representation from experience. The gap between representation and responsibility constitutes a moral dilemma. Representation is complicated by the fact that “it is a matter not only of lies told by anthropologists, however, but also of lies told to anthropologists” (Metcalf, 2002:1). When recording text, one continuously has to question the information given and then cross-check this with other sources. A method of triangulation was used where informants’ observations were used to validate data from interviews and vice versa. Informants’ accounts were also compared with one another, and this proved to be specifically useful when comparing conflicting accounts. This happened often: patients, like all of us, resort to impression management (Goffman, 1969:221). Repeating questions to informants at different times, and also asking the same questions of different people was done as a means of cross-checking information.

1.3.3 Entering the field

1.3.3.1 Gatekeepers

Through work done previously at Petrusburg by the Centre for Health Systems Research and Development (CHSR&D) of the University of the Free State, working relationships with gatekeepers, organisations and institutions (governmental and non-governmental) had already been established. These previously established relationships made access to the community of Petrusburg and its people relatively easy. During my first visit to Petrusburg, I became acquainted with both the senior professional nurse working with HIV patients at the local Community Health Centre (Bophelong) and a community home-based carer. This acquaintance came naturally, because we could all connect on a professional level and also because we shared a common interest, namely working with HIV patients on ARV treatment.

1.3.3.2 Informants

While making contact with relevant stakeholders went generally easily, identifying and recruiting informants and eventually building rapport, was obviously more challenging. It was during my second visit that the nurse, accompanied by the community home-based carer, introduced me to the patients who visited the clinic for scheduled clinical appointments. After having been introduced, I announced that I planned to conduct research among HIV patients on ARV treatment and would therefore appreciate their information and participation. When the patients were informed of my purpose, they started to view me differently and treated me as a somewhat suspect outsider who should not be trusted, because I did not share their experiences. This perception and suspicion immediately created a more awkward social space between them and me (that of potential informant versus researcher). The patients later took my information leaflet and consent forms to discuss with significant others, but were reluctant/not keen to participate in the study. A woman thus articulated her concern: “I can only talk to you if you assure me that you are not working for the Pension Department.” Another woman explained further:

> “You know why I don’t want to come to your study? I would feel guilty if I came to your interviews, because I know I would lie to you. I don’t want to talk, because I don’t want my secret life going public. Believe me, those who will come to you will probably lie to you. You won’t get the truth either, because they are scared to lose the medication or the grant[13].”

---

[13] When I discussed these reactions with the community home-based carer, I learned that some of the patients were on a social grant and my visits coincided with the very same review period as that of the Department of Social Development. Patients who were in advanced stages of

Regardless of my efforts, the attempted overt approach was unsuccessful because my research role disclosure immediately changed our social relationships and silenced voices. These preconceptions underscored the informants' reluctance to participate, and when they did participate, they provided 'idealistic' socio-cultural feedback/constructs during the interviews. It was important to ensure that informants were relaying the actual realities of their socio-cultural context and not idealistic realities (*cf.* the concerns noted in this regard by Ember & Ember, 2000:156). Facilitating the transition from ideal to real narratives would distinguish this study from those that documented results of self-reported adherence or non-adherence.

As the initial overt approach had failed during the first meetings, I decided to change my strategy and became more involved in participation. I accompanied the home-based carer on her home visits and took part in the informants' support groups, but intentionally limited any personal contact. Instead of actively engaging in personal interaction with patients, I mainly, on the one hand, recorded activities I could observe, and, on the other, spontaneous conversations that I overheard during the field trips.

The active role I played in the field turned out to be in line with the uniqueness of informants' 'in-group subculture'. This adjustment not only helped me avoid the detached, impersonal relationship challenges I had experienced at the beginning of the fieldwork, but also provided a much-needed social space *to participate* in the informants' daily activities as an insider, while however, *observing* it as an outsider. In order to build trust and rapport with the informants, and also to elicit reliable and authentic information from them, I conducted all interviews in a respectful, friendly and non-judgemental fashion. During the follow-up interviews, signs of fatigue and unwillingness to go beyond the known and the already told became prevalent. This was, on the one hand, a painful reliving of moments that

---

HIV and unable to earn a living, obtained recommendations from a doctor to receive social grants. The grants were temporary and patients were subjected to quarterly reviews to ascertain whether grants would be continued or discontinued.

had led to the contraction of HIV and AIDS, and, on the other, a facing up to the challenges of a life after infection: a mirror of the helplessness and often hopelessness of their situation.

1.3.3.3 Authorisation, ethical and confidentiality considerations

Authorisation to conduct this research at the Bophelong Community Health Care Centre was secured via the CHSR&D with its long-standing partnership with the Free State Department of Health. The study protocol of the Department of Anthropology and of CHSR&D was approved by the Research Ethics Committee of the University of the Free State.

Ethical considerations emerge in all fieldwork experiences, and require that anthropologists reflect on the possible effects of their research on the informants. Prior to the initial interviews I repeatedly explained the purpose of the study to make sure that informants understood both the nature of their involvement as potential informants, and also the benefits and risks of their participation. I particularly emphasised their right to privacy and confidentiality and that all observations would be overt. Ongoing notes and documentation were immediately made available on request. The final conclusions and recommendations from the study were discussed with and provided to all informants prior to submission of the dissertation. In respect of this study, the following ethical principles were endorsed by the researcher (*cf*. Babbie & Mouton, 2001; Neuman, 2000).

Informed verbal and written consent: Van Willigen (1986:52) points out that confidentiality and voluntary informed consent are the cornerstones of ethical research practice. Accordingly, this research adheres to the principles of ethical research practice. All interviews and discussions followed established data-collection protocols (see Annexure A). This procedure involved providing basic information to help informants make informed decisions on whether to participate in the study or not. Both verbal and written consent from each informant was obtained prior to commencement of the research. Although this was not encouraged, I also explained to the informants that, should the need arise, they could terminate their participation.

Respect of patient privacy: The especially sensitive nature of the topic of HIV and AIDS was respected, and confidentiality was maintained throughout the study. This was particularly important because, although informants disclosed their HIV status to a significant other (according to ART criteria), some did not disclose their status to their family members or the community (reasons will be discussed in the empirical chapter).

1.3.3.4 Advantages and disadvantages of indigenous anthropology

While, on the one hand, doing this fieldwork among one's own people was advantageous - because I was familiar with cultural norms and values, which might have been an obstacle to a foreign anthropologist, who would have been seen as an intruder - on the other hand, working in a field where human suffering is prevalent, even common, did raise a number of difficult questions. It was thus often problematic to rationalise and represent, and sometimes to do justice to the situation in an academic treatise. My research has, to a large extent, often been an emotional journey with the research informants. It must be noted at this point that doing long-term, in-depth participant observation among people suffering from a debilitating and life-threatening disease is not easily achievable since one must be careful not to increase their own, their families' or even the health workers' burdens. Other researchers have noted that the evolving researcher-informant relationship in field research is often conditioned by a researcher's personal characteristics such as culture, gender and age (Wax, 1979:512-520, *cf*. Li, 2008).

Culture mattered in the study

Having the same racial and cultural background as the informants is usually considered advantageous in fieldwork. However, in this study, my cultural background did not help me to gain easy access to the informants' private experiences. Two interrelated cultural accounts [direct and indirect cultural constraints] (*cf*. Ember & Ember, 2000) may provide explanations for this irony. Firstly (indirect constraints), because immoral behaviour is associated with HIV, people tend to hold strong feelings of shame and dishonour about culturally undesirable behaviour, perhaps because revealing that one had contracted HIV because of ‘culturally undesirable behaviour’ to a researcher from the same culture would activate strong negative emotions emanating from self-blame. Secondly (direct constraints), the pressure of culture stems mostly from norms that prescribe certain behaviour for individuals, and consequently they limit or prohibit the discussion of certain topics with outsiders or with a person of the opposite sex. The topic of sex behaviour, which, among other things, fuels HIV infection, is just such an issue. Talking about sex is neither customary between members of opposite sexes nor among those of different ages. Thus, because I was younger than the informants, I might have offended them as well as others who, though younger than I, were females.

Gender also mattered in this study

As a male researcher participating in the informants’ daily lives, I generally had easier access to the male than to the female informants. This also had an effect on the quality of the conversation: it was easier to have in-depth discussions with male informants than with female informants. This gender advantage in field research reaffirms the position that, in order to understand men’s life situations and experiences, more studies should be conducted by men on men, depending of course, on the nature of the inquiry.

Age was yet another personal characteristic that mattered in this study

On the one hand, some teacher-student relationships accidentally occurred during the fieldwork, these obviously triggered by my age (not calculated in figures, but resulting from my physical appearance, particularly in body build). Although the most senior informant did not know me, he took the initiative to talk to me because it is culturally considered a noble social practice for an elder to educate a younger person regarding the negative consequences of those actions that had resulted in his current health status. He saw fit to warn me so that I would not repeat the mistake he had made. He (the informant) saw me as a young university student who could take the lead in influencing and rescuing the younger generation to change their sexual practices, and hopefully so turn the tide of HIV.

It was only after this 'socialisation' process that both the researcher and the informants showed signs of a more relaxed, trusting and honest working relationship. As the interviews progressed from simply telling HIV stories to reflectively interpreting the meaning of HIV and ARV treatment, informants became more and more comfortable about sharing their private socio-cultural realities. Their openness yielded detailed and in-depth information for the study. For the rest of my fieldwork, I encountered neither any other awkward situation nor did I experience emotional uneasiness and discomfort.

The information obtained from informants was continuously verified by my own observation and the local home-based carer. I can therefore safely make the assumption, based on research observation and the informants' narratives, that realistic information was indeed given and recorded.

While observational methods yield richer data collection, the process can however also be demanding. This was especially the case in this study: informants felt uncomfortable with the use of an audio recorder and eventually allowed the documentation of observations and interviews only by pen and notebook (*field notes)*. Frequently, conversation and action occurred at the same time as I had to note what was said, to whom, in what way, with what effect, and also the kind of behaviour that was occurring. All of this transpired very quickly as part of a complex interaction among the informants. I assumed that while I was writing, I could have missed part of the interaction, or failed to record an action accurately. These demands raised the possibility of bias in how observations were made, recorded, analysed and interpreted. To minimise the said challenges, I limited note-taking during a session to writing down key words or phrases. These field jottings helped me recall the main features of the observational session and notes were subsequently converted into full field notes immediately after each session. Another means of verifying my observations and recordings was to use different methods (*see study methodology*) to obtain data.

1.4 RESEARCH AREA AND GROUP

1.4.1 Research area

The research for this study was conducted among HIV-infected patients receiving ARV treatment at the Bophelong Community Health Centre. Out of the total number of patients, only eight were prepared to participate in the study. The research group came from the Bolokanang community at Petrusburg, a historically rich agricultural centre situated 80km west of Bloemfontein on the N8 (*see* map 1). Petrusburg was named after Petrus Albertus Venter whose estate provided the money to buy the farm Diepfontein, on which the town was laid out in 1891 to accommodate the religious congregation and to serve as commercial centre for an extensive farming area. Mixed farming is practised on the 3000 square km, which was excised from the Fauresmith District in 1863. Today, the main agricultural activities are sheep farming, and the main crops, maize and potatoes. Modest quantities of wheat are harvested in a rare season when enough rain falls in winter and early spring. There are numerous salt pans in the district.

Map 1

Petrusburg comprises two separate communities: one is in the township/location (Bolokanang), which is occupied mainly by black people; the other is in the town of Petrusburg itself, occupied predominantly by white people, while a relatively small number of black people also live there. At the time of the study Bolokanang community had a recorded population of 6938, the figure being based on Census data collected in 2001 and released in 2003 (see Table 1). While the number of people living in the town has decreased, Bolokanang community has seen a marked population growth[14]. The decrease could, in the former instance, ease

---

[14] The population increase was, inter alia, a result of the forced removal of labourers or farm workers (by the farmers) from surrounding farms. This measure was taken by farmers in order to protect their property from a potential loss of a piece of the land to farm workers.

the pressure on the already stretched community resources, while the growth has, in the latter instance, contributed to heightened demands and poses a challenge to the limited resources.

Table 1: Population estimates and trends-1996-2001

Town/area	Census 1996	Census 2001	Trend
Petrusburg	1063	586	477 (decrease)
Bolokanang	4983	6352	1369 (growth)
Total	**6046**	**6938**	**892**

Associations between disease frequency within contrasting community settings have formed another focus of interest for epidemiology ontological assumption. As part of this interest, socio-cultural correlates of rural-urban distinctions and their implications for health care have provided significant problems for investigation (Ho, 2004:755). It is not surprising that there are inequalities in both health and health care in socially stratified societies: the poor communities usually have greater exposure to disease in that they live in more crowded conditions, and that they are more likely to lack the resources to access quality care. Poverty is linked to malnutrition (Hardon *et al.,* 1995:11; Redelinghuys & Van Rensburg, 2004:227). Malnutrition may be the biological result of a diet poor in protein, but such a diet is usually also a cultural phenomenon, because it reflects a society with classes of people with unequal access to the necessities of life (WHO/FAO, 2003:4).

1.4.2 Research group/biographical information

The informants comprising the ARV treatment patients were identified using a treatment-rollout register kept by the Bophelong Community Health Centre (the local health care facility). During January 2006, one of the key informants passed away. He had assumed a leadership role in our discussions and had consistently encouraged the other research-group members to participate. He was knowledgeable about HIV and AIDS. This was evident in his willingness to start HIV-awareness campaigns, which however failed because of a lack of support from local structures. This would have been the first initiative led by PLWHA. His insight added great value to the study.

1.4.2.1 Informants' language distribution

With more than eleven official languages being spoken in South Africa, it is not rare that language barriers create communication problems during fieldwork. I was, however, fortunate because I speak Setswana and Sesotho well, and, although not perfect, my command of both isiXhosa and isiZulu is also good. The eight patients involved in the study were Tswana, Sotho, Xhosa and Zulu speakers. Specific details in this regard are illustrated in Figure 1.

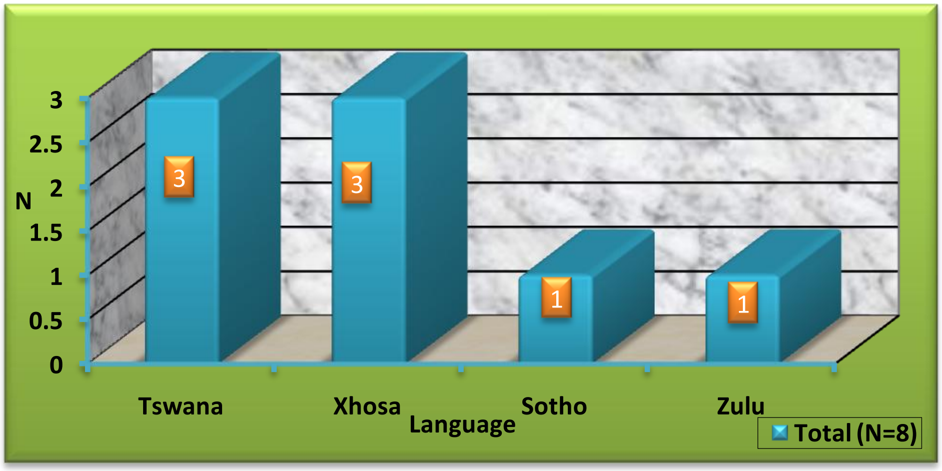


Figure 1: Informants' language distribution

1.4.2.2 Informants' age and gender

As illustrated in figures 2 and 3 respectively, informants differed both in respect of age (older than 18 years) and gender (see pages 28 and 29). The ages of informants were fairly evenly distributed, covering persons from the adolescent stage up to middle adulthood. This distribution enabled me to cover responses from different age groups. The selection criteria for the research group relied on the fact that all the informants had the same health status (e.g. HIV-positive patients on ARV treatment). Demographic factor studies, in particular in respect of age and gender, have reported contradictory results across studies (*cf*. Ammassari *et al.,* 2002:S124). Wagner (2002:603) and Gifford *et al.* (2000:389) who conducted an electronic monitoring and medication diaries study to measure self-reported[15] adherence, report that better adherence is related to age, while Weiser *et al*. (2003:284) and Ammassari *et al.* (2002:S124) noted no relation to exist between age and adherence. Younger age has been associated with both non-adherence (*cf*. Carballo *et al*., 2004:590) and adherence (*cf.* Stone, 2001:867). However, a linear relationship seems to exist between younger age - as a predictor of poor adherence - and older age (De Reuck, 2008:18; Murphy *et al.,* 2004:480). Murphy *et al.* (2004:480) state: "It may be that those who are older have greater stability in their lives, and such stability may positively impact adherence." Although it is not clear whether age, in Sub-Saharan Africa and South Africa, is predictive of adherence or non-adherence (*cf*. Edward *et al*., 2006), advancing age has been associated with improved adherence (*cf*. Orrell *et al.,* 2003).

---

[15] A technique reported by Chesney (2000a:171), as having limitations in respect of the quantifying of adherence. These techniques have the advantage of low cost and flexibility of design (questionnaire suits individual language abilities). The data are easily collected and can help determine the reason why patients are non-adherent. They assume, however, that patients can accurately recall their behaviour and are providing honest answers. A major limitation of self-reports is that they reflect only short-term or average adherence and may often overestimate adherence (Stone, 2001:867).

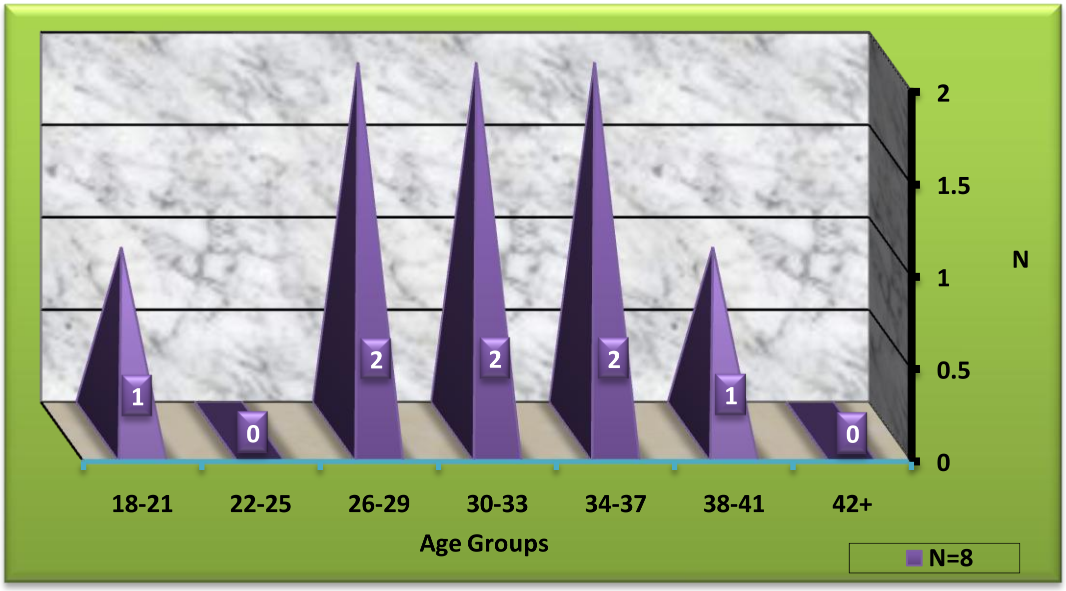


Figure 2: Age of the informants

The concept of gender has been used in the social and human sciences since the 1960s. In contemporary social science, the distinction between the biological and cultural aspects of being either male or female is very important. *Gender* is the cultural and social classification of masculine and feminine based on power and socio-cultural norms regarding women and men. More specifically, it refers to the roles, behaviours, expectations, perceptions, norms and responsibility that a society views as appropriate to women and men (Nanda & Warms, 2002:241; Risberg *et al*., 2006:2). Every culture recognises distinctions between male and female, but cultures differ in respect of the meanings attached to these categories. Culture defines gender roles, behaviours, personality traits and the expression of emotions. Margaret Mead's study on the 'biologically determined nature of gender' showed that the repertoire of behaviours, emotions, and interests involved in being either masculine or feminine is patterned by culture (1934). De Reuck (2008:42) argues that "taking gender into account -particularly in the context of treatment, care and support for HIV-infected patients is crucial for effective health services with a view to successful treatment outcomes and ultimately patient survival".

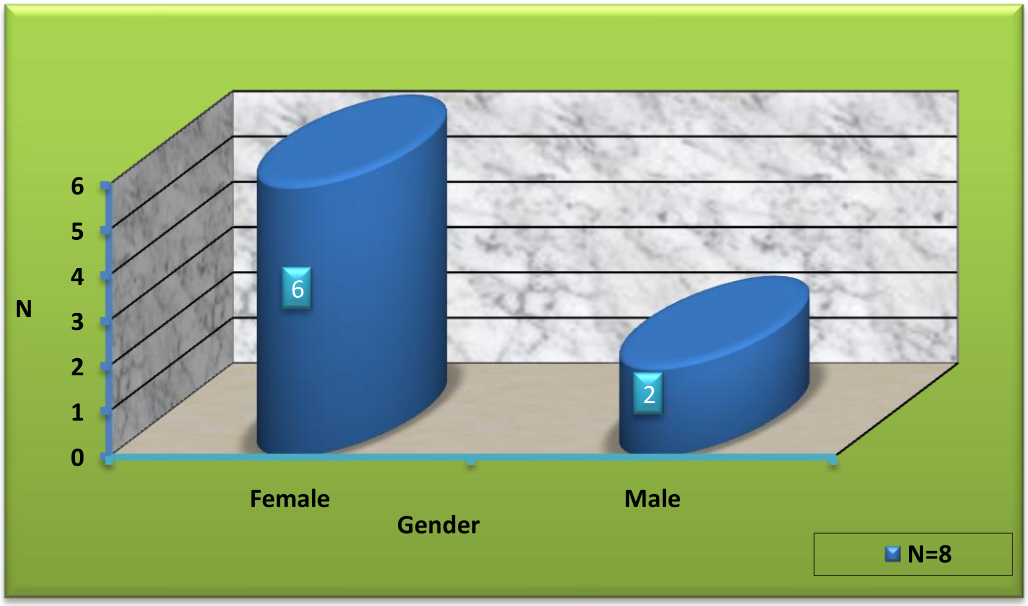


Figure 3: Informants' gender distribution

In this study, *sex* means the biological difference between men and women, particularly the visible differences in the role each sex plays in the reproductive process. These differences, especially as manifest in the gender roles prescribed by culture, will be used in this study to facilitate understanding of the potential role they can play in either protecting or making one vulnerable to ill health, depending on the context. One may term *individual* those contextual conditions in which the beliefs, expectations and behaviours inherent in a particular culture contribute to ill health, illness and social gender.

Illness and male social gender: In comparison with women, men are encouraged to drink alcohol, to smoke cigarettes, to be more competitive and to take more risks in their daily lives. In the face of suffering and pain, men are expected to be brave and display an unemotional language of distress. This may be counter-productive to HIV and AIDS, for it may lead some men to ignore early symptoms and thus perhaps not seek treatment at all, leaving them vulnerable been sick, which will result in an inability either to live up to or perform expected social roles (that of a provider). Such inability could lead men to experience feelings of uselessness (Doyal, 2001:1063).

Illness and female social gender: Conversely, in comparison to males, women are socialised to respond immediately to illness and seek treatment, and to display an emotional language of distress (Doyal, 2001:1061). Sharma and Garg (2006:118) have however noted that women in India are more likely to wait longer periods of time before seeking services and treatments in the course of an illness, and they are more likely to be at an advanced stage of HIV infection and present related opportunistic infections before they actually seek out treatment and services. In the main, it can however be said that immediate consultation with a western health practitioner may aid in the early recognition of HIV and AIDS and the initiation of ARV treatment (Doyal, 2001:1061).

There has been a growing recognition that the biological differences between the sexes extends beyond the reproductive. A wide range of genetic, hormonal, and metabolic influences plays a part in shaping distinctive male and female patterns of morbidity and mortality (Doyal, 2001:1061). Gender-specific diseases, such as cancers of the cervix and the prostate are the most obvious examples. However, there is also growing evidence of sex differences in the incidence, symptoms, and prognosis of many other health problems, for example, HIV and AIDS. One of the most important of these sex differences is the greater biological propensity of women towards contracting HIV and AIDS. Women are at a higher risk of HIV infection than men are, because of a mix of physiological factors and the gender-based power structure that may, for example, render condom negotiation with a partner either difficult or impossible. Compared with men – because of physiological factors that result in the more efficient transmission of the virus from men to women, than from women to men - women are at greater risk of contracting HIV (De Reuck, 2008:45; Sharma & Garg, 2006:117). For example, violence against women has been cited as a strong predictor of HIV (Sharma & Garg, 2006:118). Most obviously, violent sexual acts, such as rape, are likely to result in vaginal tearing or lacerations, thus dramatically increasing the risk of contracting HIV.

If health services are to meet the needs of both women and men, all sex differences need to be taken seriously in the planning and delivery of care. Biological influences are only one part of the complex matrix of factors shaping the health of women and men. Socially constructed gender differences are also important in determining whether individuals can realise their potential for a long and healthy life (Doyal, 2001:1061). Doyal (2001:1061-1063) furthermore suggests that the social and cultural distinctions associated with differences in age and gender can have significant effects on epidemiological phenomena in that health problems are often communicated to others in ways that are culturally prescribed. In one culture, for example, sick people may be expected to show their pain, while in another, they are expected to do the opposite. Furthermore, in one cultural setting, suffering due to ill health is experienced collectively, while in other settings the ill suffer in isolation (Hardon *et al.,* 1995:11).

Health-promotion policies, in particular, need to be gender sensitive if their messages are to be heard. Too many campaigns are aimed at women in their roles as the carers of others, while sadly ignoring the well-being of the women themselves. Men, too, often feel that health is women's business and that health-promotion messages are not addressed to them. HIV and AIDS campaigns have simultaneously exhorted women and men to 'use a condom' without recognising that the very real differences in power and status structure most sexual encounters (Doyal, 2001:1063). Studies indicate that although South African women are reasonably knowledgeable about HIV and AIDS (Department of Health, 2003), this does not however translate into safe sexual behaviour that will reduce the risk of HIV infection. Conditions of poverty, patriarchy and violence underlie women's vulnerability to HIV and AIDS infections (Doyal, 2001:1061; Hardon *et al*., 1995:11). If this is to change, campaigns need to be designed in ways that encourage both women and men to look both after themselves and one another. De Reuck (2008:45) echoes this view in associating sex and gender with health-related behaviour.

1.4.2.3 Informants’ marital status, educational background and religious and social affiliation

Informants’ marital status and educational background are reflected in Table 2. Although Stone (2001:868) reported that level of education is not a significant predictor of adherence, the low levels of education among informants raised concern - given the acknowledged complexity of the ARV regimen (Stone, 2001:125). Although treatment regimens for HIV and AIDS have become less complex since the advent of combined drugs in single medications and through twice-a-day and once-a-day dosing, studies on the correlation between literacy and medication adherence have shown that poor health literacy can create barriers to fully understanding health, illness and treatment, which results in medication non-adherence (*cf.* Kalichman *et al*., 1999a:272-273).

Marital status was used to understand how informants deal with challenges to adherence and disclosure within their respective social relationships (that is being married, dating or being single). To identify similarities and differences, this information was compared. This information can be used to inform the design and implementation of either an awareness campaign or an educational support programme.

Table 2: Informants' marital status and educational background

Characteristics	N=8	%
Marital status		
Married	3	37.5%
Not married, living with parents	5	62.5%
Education		
No schooling	-	-
Primary School (Grades 1-4)	-	-
Secondary School (Grades 5-8)	5	62.5%
High School (Grades 9-12)	3	37.5%
Higher Education (N Certificate, Diploma, Degree)	-	-

Informants belonged to various religious denominations, as indicated in Table 3. The information on the informants' religious affiliation will be used in the discussion of empirical findings to investigate the role religion played in patterning the informants' understanding and interpretation of both ill health and treatment options.

Table 3: Informants' religious affiliation

Denomination	Results
Dutch Reformed	4
Apostolic Faith Mission of South Africa	2
New Church	1
Methodist	1
Total	**N=8**

Poor social relationships and activities have been associated with lower adherence to both drug regimen and clinical appointments (Mehta *et al.,* 1997:1667). Kissinger *et al*. (1995:21) speculate that HIV infection is a potential cause of social isolation. Thus, social isolation may be a risk factor for decreased adherence in HIV-infected individuals.

1.4.2.4 Socio-economic conditions in the research area

The review by Lynch *et al*. (2004:7) on the correlate between income inequality and population health (*cf*. Beckfield, 2004; Lynch, 2000) notes that most of the research on income inequality and health has not addressed how income inequality might be specifically linked to different outcomes in different ways and at different times. This gap is attributed to challenges previously encountered in the assessment of economic inequalities in health. The assessment was hindered by the well-known difficulty of measuring income, traditionally the preferred indicator of economic status. While the gender and perhaps the age of individuals are usually rather obvious, their income can be much more difficult to assess. Further, they may often be more reluctant to reveal their income than, say, their religion or occupation. The resulting problem was usually addressed by using a proxy for income, such as occupation or level of education. However, such proxies have all had widely recognised limitations. For example, neither occupation nor level of education is purely economic. Educated people are usually respected for their education, regardless of whether such education is accompanied by higher income. Information on the informants' socio-economic conditions will shed light on the correlate of health of the poor as being notably worse than that of the better-off. This latter statement is underscored by Russel (2004:153) in his review on studies measuring the economic costs and consequences of illness for households and focusing on malaria, tuberculosis (TB), and HIV and AIDS. He found that "in resource-poor settings illness imposed high and regressive cost burdens on patients and their families".

Because of a scarcity of job opportunities at Petrusburg, all of the informants expressed their concern that people are often forced to take a passive role in the generation of income. The latter situation exists because the only jobs available - especially to unskilled people - are domestic duties and gardening. Such job opportunities are beyond the reach of those living with HIV and AIDS, given the nature of the work environment, the physical demands, and their health status (see Figure 4 for the unemployment status). The only means of generating an income are the government grants received by four of the eight informants; and child grants received by the remaining four (see Figure 5). The passive role can contribute to impoverishment resulting from income loss, which causes the personal consumption level to fall below minimum needs. This poor economic situation has negative implications for nutrition and so poses a challenge to ARV medication adherence. Russel (2004:147) notes that even in countries where health care services are free, household interaction with health services, and the costs people incur owing to illness, threaten the viability of a household. These costs, Russel (2004:147) opines, are primarily due to a loss of household productive labour time for patients and caregivers. The secondary costs incurred are for transportation and over-the-counter medications (Russel, 2004:150).

With regard to employment and income: while Orrell *et al*. (2003:1370), and Weisner *et al*. (2003:284) report no relation between income, work status, or low socio-economic status and adherence, Chesney *et al*. (2000a:S173) found that working outside the home, change in daily routine (especially for those with day jobs), and having no income were associated with non-adherence. In such situations patients lack the convenience of private space, especially for those whose HIV status is unknown, which might threaten their secret.

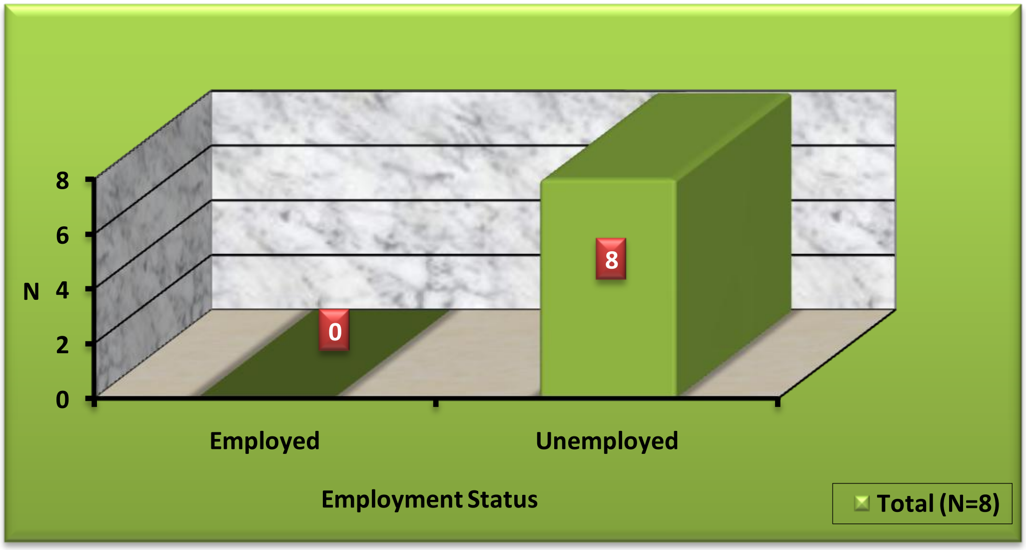


Figure 4: Informants' employment status

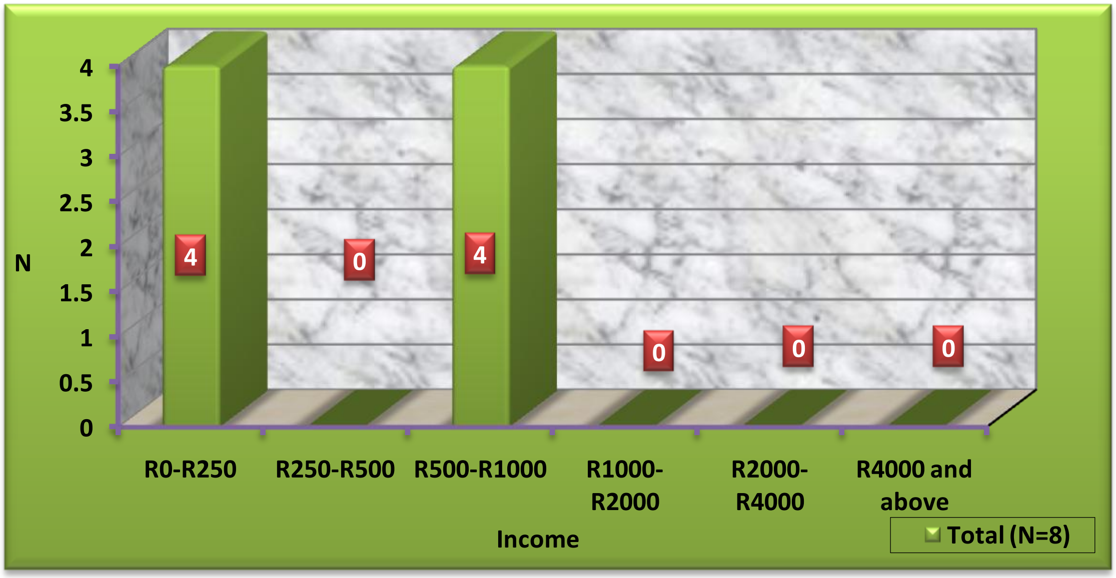


Figure 5: Informants' income status

With regard to the socio-economic status of patients and their adherence to clinical appointments, Israelski *et al.* (2001:473) found that the lower-income patients had missed more appointments. Lack of resources to get to the clinical appointments and everyday stressors associated with low income, such as buying food and paying bills, tend to diminish the importance of the medical management of HIV.

Studies investigating the role patient variables play as predictors of adherence have produced largely inconsistent results. The tendency to ascribe low adherence to (often deprived) social groups is a well-established trend in the general literature (*cf.* Horne, 1999). However, as later experience with antibiotics would demonstrate, low adherence is not restricted to certain social classes but is widespread and unpredictable (Lerner *et al*., 1998). Moreover, adherence rates vary not just between individuals but within the same individual over time (*cf.* Carrieri *et al*., 2003). Adherence is therefore best thought of as a variable behaviour rather than as a stable characteristic of an individual. Most people will exhibit low adherence some of the time (*cf.* Horne, 1999).

1.4.3 Antiretroviral treatment

While improved quality of life (QoL) has been recognised as an important outcome of the treatment of HIV (*cf*. Carballo *et al.,* 2004; Mannheimer *et al.,* 2005; Wouters *et al*., 2007), adherence to ARV treatment has been shown to be the major determinant of patient QoL (Mannheimer *et al*., 2002:1115; Mannheimer *et al.,* 2005:11). The discussion below looks at possible outplay of treatment duration, regimen complexity and patients’ attitudes towards ARV treatment adherence or non-adherence.

1.4.3.1 Treatment duration

Table 4 indicates that the informants were in the early stages of ARV treatment. The early stages of treatment have been recorded as being highly fragile (*cf*. Orrell *et al.,* 2001:483-484; 2003:1369-1375; Orrell, 2005:171-176; Roberts, 2000:157-161). Moreover, it is during these stages when the HI-viral load is very high - as it is in the beginning of ARV treatment - that strict adherence to ARV dosages and to clinical appointments is required (*cf.* Carrieri *et al.,* 2003:585-594). During the initial stages, patients have to build up a routine that includes taking medication, dealing with regimen complexity, and coping with medication side effects. Inadequate knowledge, especially given the low education level of informants (see Table 2), also poses the challenge of patients' defaulting, thus resulting in drug resistance. In some situations, ARVs are combined in a single tablet, a fixed-dose combination, which ensures that patients take multiple doses together. As a first-line treatment, ARV treatment can be delivered relatively cheaply. However, if drug resistance develops and these medicines are no longer effective, second-line ARVs may be required. The latter are far more expensive than the first-line medicines. Although high rates of adherence are recorded in the initial stages of ARV treatment intake, a potential barrier to adherence is the one noted by a longitudinal study of adherence that consistently showed a significant decrease among patients who had been 100% adherent at the start of ARV treatment (*cf*. Mannheimer *et al*., 2002:1119; Carrier *et al.,* 2003:585,588). In his study, Stone (2001:866) noted a decrease in non-adherence as a result of patients experiencing 'treatment fatigue', loss of motivation or becoming complacent.

Table 4: Informants' treatment duration

Time on ARV treatment	N=8
Less than 6 months	4
1st year	2
2nd year	1
3rd year	1

1.4.3.2 ARV regimen complexity

Research regarding treatment adherence in chronic diseases, such as hypertension, suggests that increasing complexity in the medication regimen is associated with decreasing patient adherence. Moreover, as a prescribed regimen becomes more complex, it also becomes more inconvenient and difficult to incorporate into daily living (Mehta *et al.,* 1997:1667) However, little is known about the relationship between complexity and adherence in the treatment of HIV and AIDS. It is interesting to note, from studies on predictors of adherence, that the correlate of adherence to education is inconsistent. In fact, education has even been cited as not being a barrier to adherence (*cf*. Gifford *et al*., 2000; Ammassari *et al.,* 2002; Wagner, 2002). Regimen complexity, according to Stone *et al*. (2001:125), constitutes the multiple characteristics of the prescribed regimen. These include, but are by no means limited to, the number of different medications in the regimen, the number of doses per day, the number of pills per dose, the total number of pills per day, and whether there are any food-related restrictions. This study has already acknowledged the strides made in South Africa since the advent of combined drugs, yet the lack of correlation between patients with low levels of literacy and their overcoming regimen complexity remains an issue (*cf.* Chesney, 2000:S172; Machtinger & Bangsberg, 2005).

1.4.3.3 ART-related knowledge, attitudes and beliefs

Studies conducted by Gifford *et al.* (2000:391), Wagner (2002:604) and Mehta *et al*. (1997:1667) in which they assessed factors influencing adherence to ARV treatment, recorded high levels of adherence for patients with high general knowledge about HIV and ARV treatment, thus better informed than others and for those who believe that non-adherence leads to drug resistance, which results in poor quality of life (*cf.* Mannheimer *et al*., 2002:1115; Mannheimer *et al.,* 2005:11).

According to Mehta *et al.* (1997:1667), negative attitudes about medications or illness may also interfere with patient adherence. In their study among HIV and

AIDS patients, attitudes and beliefs related to decreased adherence included the patient's acceptance/perception of the disease, and a perceived lack of benefits. On the other hand, Wouters *et al.* (2007) note that the belief that ARV prolongs life and improves QoL is associated with increased adherence.

In respect of decreased adherence it was found that – apart from the denial of necessity of treatment - it was specifically related to scepticism created by the contradictory and sometime negative messages about ARV treatment that have been communicated via paper and electronic media in South Africa (perceived lack of benefit). No doubt, such messages could have contributed to the development of negative attitudes and beliefs regarding ARV treatment. A South African study on *QoL,* with special focus in the Free State, conducted by Wouters *et al.* (2007), can be used to help influence patients' beliefs and attitudes towards ARV treatment by means of awareness and educational programmes.

1.5 NEIGHBOURHOOD AND HEALTH[16]

In the past few years, an interest in the effect of neighbourhood or area on health has increased tremendously. Anthropologists working in public health research have recognised that models of disease aetiology that focus exclusively on individual characteristics, personality and demographic or behavioural factors are inadequate in explaining the complex set of factors that cause and maintain poor health (Hardon *et al*., 1995:1; Kleinman, 1980:53). The health behaviours and outcomes of individuals, too, are influenced by the neighbourhood environment in which such individuals live (Ellen *et al.,* 2001:391). Among studies of how humans interact with the elements of their environmental challenges, Ho (2004:755) and Giger and Davidhizar (2002:185) have hypothesised that there is a connection between poor environmental control and disease vulnerability. Ellen

---

[16] I use the term 'health' in this dissertation with the understanding that it is a complex outcome that can be measured on a continuum of general to specific indicators. Among the general indicators are life expectancy, quality of life and self-rated health; among the more specific measures are mortality rates and the specific causes of death.

et al. (2001:391-395) have identified contextual neighbourhood categories that might affect health, viz. direct threats created by the unavailability of quality health care services, the neighbourhood's environment, and indirect threats through neighbourhood influences on health-related behaviour - all of which can be exacerbated by an individual's living conditions.

1.5.1 Living conditions

Since the late 19th century, public health institutions have played a major role in providing services to people living in poverty and to populations disadvantaged by race, geography, age and political systems. In the late 19th century, two issues stood out as requiring the urgent attention of government: firstly, the impact of the social determinants of health, such as poverty and lack of social support; secondly, the impact of the physical environment - particularly contaminated water, overcrowding and pollution - on the health of citizens (*cf*. Giger & Davidhizar, 2002; Ho, 2004). Redelinghuys & Van Rensburg (2004:227) observe that, while living standards have, on the whole, improved as a result of increased global prosperity, better nutrition and improved education, such improvements have not been experienced across the board. Mainly, privileged minorities have reaped the benefits of improved health; the countless masses still face poverty and the threats that it brings to their everyday health. Petrusburg bears testimony to this.

Photo 1: RDP House

This photo depicts the structure of a Reconstruction and Development Programme (RDP[17]) house, awarded to some of the informants in the study. The house has two bedrooms, a kitchen and a living area. The mother or grandmother uses one bedroom and the other bedroom is shared by the older children. All other younger siblings sleep in the living area at night. Although the informants were grateful and mentioned that their conditions have generally been better compared with residing in a shanty house (especially during winter, rainy seasons and sometimes in summer), they nevertheless noted dissatisfaction – resulting from overcrowding and a lack of both privacy and running water. While *overcrowding* relates directly to the unavailability of space and poor material circumstances, *under-crowding* may be an issue among HIV and AIDS people and may result in isolation and loneliness. Also, the fact of still having to use the bucket toilet system was mentioned as a possible threat to their health, especially to that of people with HIV and AIDS. The informants recalled how the doctors encouraged them to keep their living environment clean to optimise their chances of recovery and so to minimise opportunistic infections. This is a huge challenge facing the informants, because of the reality of their living conditions.

---

[17] An RDP house is usually, as in this specific case, a two-roomed freestanding house, owned privately but subsidised wholly or partly by the government and allocated on a needs basis. RDP houses are part of the ANC government's housing policy under the Reconstruction and Development Programme enabling poor people to own a house.

Photo 2: Streets

The infrastructure in the Bolokanang community is poor: the streets have not been tarred, and dirty water runs down the streets.

Photos 3 and 4 depict the toilet facilities used by informants and their siblings. The bucket toilets are not regularly emptied and are unhygienic, this resulting in children and adults, especially persons with a compromised immune system, falling ill more often. The informants indicated that buckets are emptied only on Fridays, and while waiting for Fridays, informants either empty buckets at the dumping site as shown in Photo 6 or alternatively, they request to use neighbours' toilets. These dumping sites are close to or behind residential backyards and close to the roads used by both people and cars (see Photo 6). The sick at Petrusburg have but limited choice when it comes to avoiding risks, such as overcrowding, stress, insufficient nutrition and housing (*cf*. Wilkinson, 2005). Stigmatising attitudes, also among health personnel, constitute barriers to care not caused by patients' cultural beliefs. Adherence has less to do with cultural values than with social circumstances caused by broader structural factors (Farmer & Nadell, 1998:1014). These factors include lack of adequate resources in the health care system to ensure patient care. For those employed prior to falling ill, this often results in unemployment, further impoverishment and insecurity as a result of sickness. Even when people do have employment, jobs are insecure and the payment low. This is also noted by Nattrass in Khayelitsha, Cape Town (2005:13).

Photo 3: Toilet facilities (bucket system)

Photo 4: Emptying a used bucket

Photo 5: Emptied bucket

Photo 6: Dumping site

People living in such impoverished conditions are especially at risk of ill health, since they are subjected to often unliveable conditions, such as inadequate or overcrowded dwellings, insufficient and unsafe water supplies, poor or lacking sanitation, and high levels of air and water pollution. All of these leave patients vulnerable to opportunistic infections and further pose a challenge to ARV medication adherence.

1.6 OUTLINE OF THE CHAPTERS

The dissertation will unfold in four chapters:

- Chapter 2 provides an overview of the relevant literature in order to obtain the necessary theoretical background for the contextualisation of the study. The chapter addresses the '*explanatory model*', the theoretical point of departure of this study, for understanding medication and appointment adherence in patients with chronic diseases. Apart from the theoretical framework, terminologies are also clarified.

- Chapter 3 investigates causal reasoning and illness understanding in the Petrusburg community in order to understand how patients/informants deal with seemingly conflicting biological and social theories about HIV, AIDS disease and ARV treatment. Furthermore, the chapter elucidates the cosmological assumptions that shape the perceptions of the informants, particularly with regard to the notion of cause and effect.

- Chapter 4 presents the empirical findings. The data from the sample of eight men and women are analysed to examine the role that a patient's socio-cultural context plays in respect of treatment adherence or non-adherence.

- Chapter 5 interrogates the context of people-centred community engagement and provides some significant conclusions and recommendations from the study. Lastly, possible topics for future studies are suggested.

CHAPTER 2: ANTHROPOLOGICAL PERSPECTIVES ON THE STUDY OF HIV AND AIDS AND CLARIFICATION OF CONCEPTS

2.1 INTRODUCTION

This chapter discusses various approaches to studying and applying medical anthropology in an attempt to understand the connections between the micro and the macro levels of the epidemiology and aetiology of HIV, AIDS and ARV treatment. The importance of including macro-level forces in anthropological micro-level analysis is emphasised. The role of the anthropologist in the clinical environment is explored, and it is argued that combination rather than opposition of applied biomedical and ethnomedical approaches (as illustrated by Figure 6), would be the most appropriate and useful approach. Anthropologists who study illness and health are often, according to Ember and Ember (2005:513-514), classified into two categories. First, there are those who are more relativistic in their approach, holding the view that culture has such a profound influence on symptoms of ill health, its incidence and treatment that there are few - if indeed any - cultural universals in respect of illness. If each culture is unique, we should expect conception and treatment of ill health likewise to be unique, thus decidedly unlike beliefs and practices in other cultures. Secondly, there are those with a more universalistic approach who see cross-cultural similarities in both the conceptions and treatment of illness, this despite the unique qualities (particularly in the belief system) of each culture[18].

---

[18] The concept of *culture* has been extensively defined – in 1952 Kroeber and Kluckhohn already listed and surveyed nearly 300 different definitions of the term, however the is still a large of uncertainty in its use. I am aware of the debate and continuous conversation in anthropology on the nature, meaning and place of culture (*cf.* Borofsky *et al*., 2001:432-444). For the purpose of this study, it is accepted that *culture* is the acquired knowledge people use to interpret experiences and to generate behaviour (Haviland, 2000:34). As a member of a particular society, people learn how to view the world, how to experience it emotionally, and how to behave in relation to other people, God, supernatural forces and the natural environment (Ember & Ember, 2000:146; Haviland, 2000:34; Spradley, 1980:6).

Although anthropology is quite often characterised as being relativistic in nature, the fact of universal human imperatives cannot be ignored. So, too, cross-cultural similarities and differences in the conception and treatment of illness cannot be ignored either. This is also the point of departure of Kleinman *et al*. (1978), Kleinman (1980), Helman (2000) and Hardon *et al.* (1995) in the development and refinement of a multifaceted explanation of adherence or non-adherence. The aforesaid approach, known as the explanatory model for understanding medication adherence in patients with chronic diseases, represents the theoretical framework that guides this study. Apart from the theoretical framework, terminologies will also be clarified in this chapter.

2.2 THE ANTHROPOLOGICAL PERSPECTIVE

Beginning in the latter part of the 19th century, modern medicine came to be increasingly preoccupied with micro-organic agents as the cause of disease. With attention being concentrated so heavily on direct and immediate causes of diseases, such as the effects of microbes on body tissues, interest in the social and cultural contexts of medicine declined accordingly (Lieban, 1973:1034). However, in more recent times, there has been a marked upsurge in research (by both medical and social scientists) that focuses on the social and cultural aspects of health and disease. This, according to Kleinman (1980:18-19), has been stimulated by problems connected with western medical training and practice programmes in the diagnosis and treatment of health problems.

Although health and disease are related both to socio-cultural and biological factors (Lieban, 1973:1031; McElroy & Townsend, 1985:5), anthropologists study them only as social and cultural phenomena in that they (anthropologists) view health and disease as measures of the effectiveness with which individuals or groups, combining biological and cultural resources, adapt to their environments (Lieban, 1973:1031; McElroy, 1990:244). According to Lieban (1973:1031), interest in the social and cultural dimensions of ill health reached a peak in the western world during the 20th century, stimulated by the public-health problems can to a large extend be associated with the Industrial Revolution. It was during this time that scientists started realising the importance of the socio-cultural dimensions of medicine and health. Not only did scientists emphasise the need for scientific investigation on the impacts of social, cultural and economic conditions on health and disease, but they also emphasised that society had the obligation to assure the health of its members. They thus advocated social intervention both to promote health and to combat ill health (Kleinman, 1980:ix).

Investigation into the above-mentioned aspects, fall within the framework of medical anthropology. Hardon *et al*. (1995:5) defined medical anthropology as ‘’the study of human health and disease, health care systems and bio-cultural adaptation’’ (*cf*. also the definitions of Kleinman, 1980:ix-xvi; Sargent & Johnson, 1996:ix-xxi). Although medical anthropology according to McElroy (1996:759-762) ‘’has since the 1960s developed three major theoretical orientations, namely medical ecology, applied medical anthropology and ethnomedicine, other important theoretical approaches deemed important for this study include cultural interpretive theory and critical medical anthropology’’.

Anthropologists who use an ecological perspective to understand disease patterns, view human populations as both biological and cultural entities, and study the interaction between ecological systems, health and human evolution. A systemic approach views culture as one way of responding to environmental problems, while also acknowledging that the genetic and physiological processes carry equal weight. Key concepts in medical ecology are ‘’adaptation to changes, modifications and general well-being in an environment. Medical ecology assumes that biomedical disease categories are universal. Disease rates are measured, compared over time and across geographical space and correlated with changes in settlement patterns and subsistence’’ (McElroy, 1996:760).

Applied medical anthropology deals, ‘’on the one hand, with policy issues of intervention and prevention, the analyses of socio-economic forces, and with the influence of power differentials on health care access. On the other hand, the difference between basic and applied research in this regard is that an applied medical anthropologist deliberately advocates on behalf of the community (McElroy, 1996:762). While some applied research may be theoretical in orientation, others only employ theoretical frameworks. One notable framework is the political economy of health, which was influenced by Marxist dependency theory. This approach analyses the impact of global economic systems, particularly capitalism, on local and national health. Political economists argue that change programmes should not be attempted unless the social production of illness and poverty within the larger dynamics of class interaction or colonialism are also studied'' (McElroy, 1996:762).

Ethnomedical[19] analysis focuses on health beliefs and practices, cultural values and social roles. Although originally limited to the study of primitive or folk medicine, it has recently come to mean the health maintenance system of any society. Ethnographies encompass beliefs, knowledge and the values of specialists and lay people, the roles of the healers, patients and family members,

---

[19] Anthropological research has identified some of the characteristics that systems of ethnomedical knowledge display. First, ethnomedical systems, far from being wholly homogenous, are characterised by intracultural variation in illness interpretation and management (Garro, 1986:353; Vecchiato, 1997:185). This means that local medical knowledge does not consist of a normative body of medical axioms universally and homogeneously followed by the members of a society. Rather, the structuring of or contextualisation of an illness occurrence is shaped by individual idiosyncrasies, social expectations, economic constraints, and ecological determinants. Second, local medical knowledge is not shared equally among all members of a community. A distinction should be recognised, for example, between curers and non-curers. In most cultural traditions, professional curers are repositories of a more extensive body of traditional medical knowledge than are laymen (Finkler, 1984:197). Third, systems of traditional medical knowledge are not immutable; they are, rather, characterised by the same dynamics of continuity and change as any other cultural subsystem. Patterns of ethnomedical knowledge are thus modified by the constant incorporation of new health-related ideas and practices, including the integration of selected features of biomedicine into traditional curing (Vecchiato, 1997:186).

and the symbolic and interpersonal components of the experience of illness (McElroy, 1996:762).

2.3 EXPLANATORY MODEL

A key theoretical component in ethnomedicine is the so-called ‘explanatory model’, a model developed and introduced by Arthur Kleinman in his influential book *Patients and healers in a context of culture*, published in 1980*.* Although the model later met with some criticism, from, *inter alia*, Kleinman himself (1995), it is nevertheless a useful tool when used in combination with other approaches. Kleinman has explained the purpose of the model as a useful way of looking at the process by which illness is patterned, interpreted and treated (1980:105)*. Explanatory model* is defined as the “notions about an episode of illness and its treatment that are employed by all those engaged in the clinical process”, namely patients, healers and other social members of their local social world (Kleinman, 1980:105; Kleinman & Seeman, 2000:236). They continue by indicating that the interaction between the explanatory models of patients and practitioners are central components of health care. Behind the concept of the explanatory model is the recognition that individual patients and their families (often) have their own categories of ill health, which may differ from those of clinicians, and these differences are seen as impediments to health care delivery (Helman, 2000:101, 107, 111; Morgan, 1982:56-58). The practitioners’ explanatory models tell us something about how they understand and treat disease[20], and those of the patients and their families tell us how they make sense of given episodes of illness, and how they choose and evaluate a particular treatment. Explanatory models can thus been seen as social-cultural constructions of reality (Berger & Luckmann, 1966:51-55). They are notions about the causes of illness, the diagnostic criteria, and the treatment options that both patients and physicians bring to the clinical encounter, which include distinct ideas about the cause

---

[20] Once the disease is explored in one particular environment, the aim is to make cross-cultural comparisons to seek generalisation about these fundamental human experiences (Kleinman, 1980:8, 111).

aetiology, symptom onset, pathophysiology, course and treatment (Kleinman, 1980:105).

In a clinical encounter, the explanatory models held by practitioners, patients and family can, and do indeed, often differ. The communication and negotiation of decisions in respect of managing illness lead to the cultural construction of illness. While health care practitioners would draw from their formal medical training, explanatory models of patients are influenced by personality factors and culture (Ember & Ember, 2000:146; Haviland, 2002:34; Kleinman, 1980:105; Spradley, 1980:6). In other words, it is through their culturally defined explanatory models that patients assign meanings to symptoms of illness and the treatment thereof (Hardon *et al.,* 1995:13; Young, 1980:102). Explanatory models are flexible as they change throughout the process of healing as new information becomes available. Imbalances in power can result in that practitioners do not change their explanatory models as easily as do patients (Kleinman, 1980:107). Kleinman has argued that incongruence between patients' and providers' viewpoints may negatively influence patient adherence, satisfaction, and the use of the health facility. The importance of this point has been well documented by social scientists (*cf*. Anderson *et al*., 1995; Christensen, 2001; Hardon *et al*., 1995; Helman, 1996, 2000; Hunt & Arar, 2001) who study the ways people understand and respond to chronic illness. These researchers have found that people's illness explanations of chronic illness are highly context-specific, firmly situated within their specific life histories and social and environmental contexts, and synergistically produced within the context of ongoing experiences in pursuing treatment. The following section overviews explanatory models in relation to treatment and help-seeking behaviour.

''In order for medical treatment to be acceptable to patients, it must make sense in terms of their explanatory models'' (Helman, 1994:111; Kleinman, 1980:105). Treatment adherence or the success of treatment medication is, in Helman's (1994:141) view, ''often evaluated differently by doctors and patients. The disappearance of an identifiable physical disease may not necessarily be accompanied by the disappearance of illness. Doctor-determined criteria of adherence may differ from that of the patient who may rather use ‘quality of life’ criteria, such as effect on family life, social life, work, sex and sleeping. Because of contrasting views, what a physician considers to be a successful treatment may sometimes be seen as failure by patients, especially if it interferes with any of the aforesaid ‘qualities of life’’ (Helman, 1994:141).

According to Kleinman (1980:122-124) and Helman (1994:111), non-professional explanatory models tend to be idiosyncratic, changeable, and heavily influenced by cultural and personal factors. These authors suggest that medical explanatory models (professional models) are based on “single, causal chains of scientific logic”. They further note that explanatory models are subjective, representing the reality of the illness to individuals, and that they are fluid and dynamic rather than fixed, and represent subjective interpretations of experiences, and, conscious and tacit knowledge. Although explanatory models of individuals may vary, they share similar features among those who belong to a common culture (Dela Cruz & Galang, 2007:119; Kleinman, 1980:105-106).

There is evidence that dissonance between the patient’s and the physician’s explanatory models may negatively affect help-seeking behaviour (Plowden, 2003:27), treatment compliance (Kleiman *et al.,* 2006:146), satisfaction (Callan & Littlewood, 1998:10-11) and culturally sensitive clinical practice and care (Bhui & Bhugra, 2002:7). Kleinman (1980:106) argues that ‘’explanatory models are much more easily elicited in patients’ homes by a researcher who is not involved in the delivery of medical care to the patient, and who expresses a genuine, non-judgemental interest in the patients’ perspective and who voices the conviction to patients that knowledge of the explanatory model is important to plan the appropriate treatment regimen’’.

Kleinman (1980:107) initially presented his explanatory models approach as a tool for enhancing communication between patients and providers. Clinicians were encouraged to elicit patients’ explanatory models, then articulate their own biomedical explanatory model for the patient, discuss the differences and similarities between their respective models, and, finally, negotiate a response to the patient's condition. Hunt and Arar (2001:349) acknowledge that the explanatory models have since gained popularity in the clinical literature; however, while Kleinman's discussion emphasised scrutinising both the patient and the clinician perspective - as the explanatory model is commonly employed - only the patient's viewpoint is examined, and there is no earnest consideration of the clinician's perspective. Rather than being used as a technique for communicating between equally legitimate perspectives, the explanatory model approach is frequently used in clinical research as a means of explicating patient perspectives in terms that are almost diagnostic. The underlying goal of such research seems to be to render 'differences' comprehensible from the biomedical perspective so as to promote better control of patient behaviour (*cf.* Engel, 1977; Gary, 1994; Hahn, 1995).

In this study Kleinman's explanatory model approach is used to explore *experiences, causes and symptoms of illness*. While Kleinman's model is of some value, it should be emphasised that its scope is limited: the framework has too narrow a focus on illness-related behaviour, and concentrates mainly on the micro level of experience. Instead, it is necessary to widen the scope by including the socio-cultural issues that influence health and disease (as proposed by the ethnomedicine approach in medical anthropology described above), and to acknowledge the anthropological assumption of the importance of a holistic view. The focus of this study is not only on the clinic, but also on individuals, and moreover on patients specifically as members of households and as actors in a wider network, such as a therapy-managing group. In other words, the study will follow a more holistic approach to the study of the understanding of disease or illness and of therapy management.

Holism can take many forms (McElroy *et al.,* 1985:xvii), but the most basic assumption is that for any particular outcome or phenomenon to be explained, there are various interrelated factors at work (Hardon *et al*., 1995:1-2). In practice, it means that anthropologists will collect a great deal of socio-cultural context information (e.g. economic features, social relationships, cultural belief systems and other aspects of a community). The holistic perspective often leads anthropologists to be highly critical when other disciplines appear to adopt a more single-factor explanation of illness conditions and individual health care responses. Because health and disease are related not only to biological factors, but also to cultural resources and social behaviour that utilise these resources, physicians and anthropologists share mutual interests. Lieban (1973:1033) offers the following explanation: "Disease and its treatment are only abstract in the purely biological process; such facts as whether a person gets sick at all, what kinds of disease he acquires and what kind of treatment he receives depend largely on social factors".

In the collaboration between physicians and anthropologists, physicians' primary concern is the ways in which human behaviour affects the maintenance of health and the occurrence and control of diseases (Lieban, 1973:1035), while anthropologists' involvement is inter alia in etiological studies, cultural interpretive and critical medical anthropology. There is however another side, one in which problems are defined not by the effects of human behaviour on the status of health and disease, but on the indications about human behaviour that can be observed/perceived in response to the states of health and disease. Health and disease are fundamentally connected with the reproduction, quality, preservation and loss of life. In view of the significance of such phenomena for human societies, it is not surprising that anthropological studies of health and the occurrences and means of coping with ill health can involve one deeply in how people perceive their world, in the characteristics of human social systems, and in social values (Lieban, 1973:1035). Anthropology is thus not only a way of viewing the status of health and disease in society, but it is also a way of viewing culture and society.

While the ethnomedical approach has on the one hand been criticised for being a solely theoretical approach in applied medical anthropology unable to apply itself beyond the academic sphere and impossible to apply to a clinical perspective (Chrisman & Johnson, 1996:93), medical anthropologists, on the other hand, are often criticised for being uncritical of biomedicine (Sargent & Johnson, 1996:xiv). In fact, Scheper-Hughes and Lock (1987:30) argue that one of the biggest challenges confronting medical anthropology is “to come to terms with biomedicine, to acknowledge its efficacy when appropriate while retaining a constructively critical stand”. It is necessary, both for the anthropologist and for the health professional, to acknowledge that knowledge, including biomedical knowledge, should be regarded as a cultural construct and not as a truth per se (Pelto & Pelto, 1997:147). It is our task, Singer (1990:185) argues, not only to understand medicine, but also to challenge and change it. It is not true - as is often argued within the biomedical paradigm - that anthropology makes for ‘interesting stories’, whereas epidemiologists and biomedical practitioners present the ‘real stuff’ (Heggenhougen, 2000:1171). In addition, medical (clinical) and interpretive anthropologists, such as Arthur Kleinman, have been criticised for not taking larger issues of power and domination into account when exploring patient/practitioner relationships (Baer *et al.,* 1997:25). It is essential for all anthropologists, whether they are working in an academic or a clinical environment, to realise that they too see the world through ‘cultural’ glasses. This realisation must be an integral part of our analysis. However, I will still argue that the ethnomedical approach plays a critical role in developing and applying anthropology.

2.4 CLARIFICATION OF CONCEPTS/CONCEPTUALISATION

2.4.1 Culture and society

In order to facilitate the understanding of the socio-cultural context of the people of the research area as stated, the study needs to clarify the following two aspects, namely (i) the meaning of the difference in nature between cultures and societies, and (ii) the role of various cultures in the health or medical setting.

According to Abdel-Fattah *et al*. (2003:48), cultures and societies can broadly be typified as being either *individualistic* or *collectivistic*[21] in nature. Collectivism is defined as a ‘’situation where people feel they belong to a larger in-group or collective that cares for them in exchange for loyalty and vice versa’’. An essential attribute of collectivist cultures/societies is that individuals may be induced to subordinate their personal goals to the goals of some collective, which is usually a stable in-group (e.g. nuclear family, extended family and/or community). Consequently, much of the behaviour of an individual may concern goals that are consistent with the goals of such an in-group (Triandis *et al.,* 1988:324). In individualistic societies (situations where people are mostly concerned with themselves and their immediate family), there are more in-groups available from which an individual may choose. An individual’s behaviour can thus simultaneously be consistent with the goals of several in-groups. Individual goals may or may not be compatible with group goals, and, if there is a discrepancy, priority will be given to individual goals. Furthermore, the relationship between an individual and the in-groups of choice tends to be less stable, as an individual can leave a group if costs exceed benefits (Körner, 2007:140). As a result of the differences in the nature of the relationship between the individual and the in-groups, behaviour, according to Triandis *et al.* (1988 324-326), is likely to differ in individualist and in collectivist societies.

---

[21] I am aware that during the late 1950s and 1960s, national character and typical personality were broadly condemned, breathed their last, and were ultimately relegated to the dustbin of bad social science (*cf.* Seymour-Smith, 1990:66). Many consider such inquiry to be no more than unscientific stereotyping, usually with malevolent intent and effect (Lassiter, 1999). Since then, scholars have, nevertheless, been sustaining and redirecting group personality inquiry (*cf.* Körner, 2007; Triandis *et al.,* 1988). Scholars writing on these topics have taken a humanistic, liberating or empowering approach. They have been specifically interested in identifying and explaining African psychological processes, personality characteristics, and the process of African cultural adaptation to social conditions. This study is cautious not to use these notions either to perpetuate unfounded categorisation or in a demeaning way. The selective use of this information is to shed light on the contextual dynamics of patients’ management of illness.

Although individualism and collectivism are presented as two separate and extreme sides of a continuum, both types of cultures/societies have common notions, such as self-reliance and interdependence, but the meanings of these concepts differ: in individualist cultures/societies self-reliance means freedom to 'do one's own thing' and compete with others; in collectivist cultures/societies, on the other hand, self-reliance means not being a burden to the in-group. Interdependence in individualist cultures/societies is understood in the context of social exchange, whereas in collectivist cultures/societies it is understood in terms of duty and obligations (Triandis *et al.,* 1988:325). In line with these views of the relationship between the individual and the in-group, two broad, culturally shared views of the self have been developed, depending on one's view of the self in relation to others (Körner *et al*., 2007:140). In individualist cultures/societies, the self is mostly construed as autonomous, independent, and separate from others. For the independent self, behaviour is organised around a person's own thoughts, feelings and actions. By contrast, the self, in the collectivist cultures/societies, is construed as denoting being fundamentally interdependent, that is, as the self in relation to others. This entails viewing oneself as part of a social network where one's thoughts, feelings and actions are dependent on the thoughts, feelings and actions of others in the relationship (Körner, 2007:140). This view of the self as being interdependent assigns priority to the relationship between self and others, in other words, the self is perceived as whole only in relation to others.

Generally, Anglo-American and European cultures have been classified as predominantly individualistic, whereas most Asian and African cultures adhere to a predominantly collectivistic culture (Triandis, 1989:325). However, modernisation, urbanisation, acculturation, diffusion, among others, have decreased the meanings of these predominantly ascribed labels. It is therefore safe to say that societies do not exhibit these cultural forms either exclusively or in pure terms. Both collectivist and individualist values co-exist and interface with each other.

Regarding the second aspect referred to earlier (*cf*. culture and society [ii]), Tseng and Streltzer (2008:8-9) point out that, in the medical setting, there are three cultures present: (i) the *culture of the patient*, (ii) *the culture of the physician*, and (iii) the *medical culture* in which the clinical work is carried out. These different cultural dimensions exert strong influences during the clinical encounter.

In addition to individual factors – e.g. education, medical knowledge and personal experiences - *the culture of the patient* will, for instance contribute to the understanding of illness, to the perceptions and presentations of symptoms and problems, and to the reactions and adjustments to ill health. The patients' expectations of the physicians, their motivation for treatment, and compliance with treatment recommendations are also influenced by their culture (Tseng & Streltzer, 2008:8). T*he culture of the physician*, underpinned by his/her individual style, personal beliefs, and professional knowledge, will shape the particular pattern of interaction and communication with the patient. For example, a physician might have personal biases regarding a patient of a particular gender, race or sexual orientation. This can explicitly or implicitly affect his/her attitude towards the patient, his/her understanding of the patient's problems, and how s/he cares for the patient (Tseng & Streltzer, 2008:8). *Medical culture* includes regulations, customs, attitudes and practices that have developed within the medical services setting underpinned by medical theory and research. Biomedical practice in general, for example, is strongly embedded in the medical culture which, in turn, is supported by a structured medical system. Most clinicians have become accustomed to living within this largely invisible cultural system and may be unaware of its influence on their practice - to the extent that it will often take an outsider to recognise the existence of the medical culture (Tseng & Streltzer, 2008:9).

The distinction between disease and illness is, in Kleinman's (1980:104-118) views, conceptually important in the study of ethnomedicine. Clarification of concepts will be dealt with in the next section.

2.4.2 Illness and disease

An integral part of the explanatory model is the conceptual distinction it makes between *disease*, *illness* and *sickness*. Despite this, studies of public health use these concepts as interchangeable alternatives (Kleinman *et al.,* 1978:252). According to Wikman *et al*. (2005:450-451), methodological considerations (based on different sources of data, register or survey), the use of different informants (physicians or patients), and differences that exist in theoretical points of departure (medical symptoms or social consequences for the person) are responsible for the aforesaid state of affairs. In terms of the anthropological point of departure (Eisenberg, 1977:10-14 & Hardon *et al*., 1995:12), *illness*, *disease* and *sickness* capture different aspects of ill health. The following discussion analyses the distinction made between the 'patient' and 'doctor' perspectives during a clinical encounter, and with a focus on the resulting challenges that these pose in respect of treatment adherence.

In terms of the anthropological assumption, the concept *illness*, according to Hardon *et al.* (1995:12), reflects the patient's perspective (the emic[22] approach or an insider's view of culture). It is influenced by the cultural, social and emotional context in which it occurs, and further by an individual's background and personality (*cf.* Hardon *et al.,* 1995:12; Seymour-Smith, 1986:92). It is the ill health with which persons identify themselves, and is often based on self-reported mental or physical symptoms. In this case, the individual's culture provides an aetiology, a diagnosis, preventative measures and a regimen for healing conditions (Hardon *et al*., 1995:12). When speaking of illness, it is thus important to include not only the patient's judgement about how best to cope with HIV, AIDS and ARV treatment, but also the practical problems in his/her daily environment.

---

[22] Emic analyses are views that stress the subjective meanings shared by a social group and its culturally specific model of experience (Seymour-Smith, 1986:92).

‘’*Illness* is the subjective response of an individual, and those around, to his/her being unwell, particularly in respect of how s/he and the others around interpret the origin and significance of this event and how it affects his/her behaviour and relationships with other people. It includes not only the patient’s experiences of ill health, but also the meaning s/he assigns to that experience’’ (Helman, 2000:83). According to Helman (1990:107) people who suddenly fall ill might ask themselves: “Why me? Have I done anything wrong to deserve this?” Or even, in some societies: “Has anyone caused my ill health?” ‘’Both the meaning assigned and the patient’s emotional response to the symptoms are influenced by his/her own background and personality, and also the cultural, social and economic contexts in which the symptoms appear’’ (*cf*. Hardon *et al*., 1995:13). The patient’s perspective on ill health - in Mabunda’s view (2001:12) - is usually part of a much wider conceptual model used to explain misfortune. In some societies all forms of misfortune are ascribed to the same range of causes: a high fever, incurable disease, coughing, which, on the one hand, is associated with HIV and AIDS, and, on the other, might also be blamed on witchcraft or divine punishment for some moral transgression. The similarities of symptoms between AIDS and other socio-culturally ascribed illnesses contribute to the uncertainty and ambiguity regarding HIV and AIDS diagnoses and treatments.

In order to assist towards understanding these embedded indigenous meanings of illness; Bury (2001:268) calls for a narrative approach, and in this regard distinguishes three forms of illness narratives. The *contingent narrative* has to do with ‘’beliefs and knowledge about factors that influence the onset of ill health, its emerging symptoms and its immediate, proximate effects on the body, the self and on others’’. Such contingent narratives tell how patients and those close to them have come to terms with the symptoms and consequences of the illness or what Bury (2001:271) refers to specifically as the *practical and emotional consequences of managing symptoms of ill health every day*.

Second is the ‘*moral narrative*’ which introduces an evaluative dimension to the links between the personal and the social (Bury, 2001:274). A narrative of this nature presents moral or religious consideration and tells about the shame and the blame.

Finally, *'core narratives*' take into account the language, referents and symbols so as to identify a narrative form - e.g. whether an epic, tragic or comic narrative (Bury, 2001:275). This third type of illness narrative might lead to concentrating too intensely on the form, with the risk of losing sight of the meaning.

The co-existence of these diverse causal explanations across domains (and cultural contexts) may be further anticipated by the fact that the epidemiology of disease emergence is, in part, socially produced (Green, 1999:21). Because the transmission of disease in humans occurs through both socio-structural mechanisms (e.g. unequal access to nutritional and medical resources) and biological mechanisms (e.g. transmission of pathogens), it seems reasonable to expect that causal explanations for illness and disease would include both physical and social/interpersonal factors. Poverty and inequality may also shape the cultural beliefs concerning causal explanations for illness (Ashforth, 2005:1).

Kleinman (1988:31) and Liburd *et al.* (2004:220) view illness narratives as one of the methods by which we can obtain insight into the perceptions and experiences of individuals living with HIV and AIDS. In this study, I used the illness narrative framework proposed by the anthropologist and psychiatrist, Arthur Kleinman. Kleinman (1988:31) proposes five anthropological categories (*see* Appendix B: Interview Guide) that guide discussion in order to gain a deeper understanding of patients' views and the social realities of dealing with illness. Kleinman (1988:31) describes these categories as life history[23], patient and family explanatory

---

[23] *Life histories* are brief synopses of individuals' lives that include their major continuities and changes in attitude, personalities, major life goals and obstacles, and their earlier experiences of coping with illness and other serious conditions (Kleinman, 1988:11). A diagnosis of HIV is a significant life event that causes patients to re-examine their life behaviours, future plans and options.

models[24], symptoms and symbols[25], personal and interpersonal significance,[26] and culturally marked disorder[27] (*cf*. Liburd *et al.,* 2004:220-221).

Disease, on the other hand - as defined by Wikman *et al*. (2005:450) and Hardon *et al*. (1995:12) - is a condition that is diagnosed by a physician or medical expert. Ideally, this would include a specific diagnosis according to standardised and systematic diagnostic codes. It is based on scientific rationality and assumes that diseases are universal in form, progression and content (Kleinman 1980:73). In addition, this would in most cases also mean that the specific condition has a known biomedical cause and, often, known treatment and cures (Wikman *et al.,* 2005:450). According to Helman (2000:79), ‘’those who practise modern scientific medicine form a group apart, with their own values, theories of disease causation and treatment. As students in the process of medical education, they undergo a form of enculturation in which they gradually acquire a perspective of ill health, based on a predominantly biomedical[28] paradigm, in all likelihood

---

[24] *Patient and family explanatory models* are informal descriptions of the occurrences of a particular illness. Exploring with informants why they believe they contracted HIV exposes important disconnections between the biomedical understanding of disease aetiologies and indigenous views of illness causation (*cf.* Kleinman, 1988:12).

[25] *Symptoms and symbols* are accepted knowledge about the body, self, and their relationship to aspects of the world. How informants interpret changes in their bodies, and whether changes signal serious chronic diseases or conditions that can be quickly resolved, have implications for how they use the health care system (pattern of resort), how and what medication they take, and their general orientation to preventative health care (Kleinman, 1988:14).

[26] *Personal and interpersonal significance* involves factors external to the individual and how these factors influence individual experiences of living with an illness. Having HIV can affect one’s employability and job security, sex appeal and other social relationships (Kleinman, 1988:15).

[27] A *culturally marked disorder* is the label assigned by an individual’s culture to a specific episode of illness as not normal. How common or normal an illness is perceived to be, depends on the social context in which the illness occurs (Kleinman, 1988:15).

[28] Biomedical paradigm: central to biomedicine - in the words of Worsley (1982:321) - is the notion that “the body is like a machine in which the parts sometimes break down; treatment then consists of the repair or replacement of the broken parts (surgery) or of destroying the

shared by the majority of the medical fraternity, and that will last throughout their professional lives. They also acquire a high social status, high earning power and the socially legitimate role of healer, which carries with it certain rights and obligations''. Some of the basic premises of the medical perspective further noted by Helman (2000:79) include: ''scientific rationality; the emphasis on objectivity and numerical measurement; the view of diseases as entities; and an emphasis on the individual patient, rather than on the family and/or community''.

However, it should be mentioned that there are limitations to this ideal in medical practice. Firstly, there is the fact that a number of medical diagnoses have to be based on subjective information from the patient concerning his/her pains and feelings (Wikman *et al.,* 2005:450). Secondly, this perspective does not, in most cases, include the socio-cultural or psychological dimensions of the disease, the context in which it appears, or its socio-culturally defined meaning (Kleinman, 1980:105). Furthermore, ''disease is thought to affect single individuals (even when it attacks a whole population), while illness is thought to affect others as well (e.g. family, social networks, even at times the entire community). In some cultures, it is believed that illness is constituted by both the infected person and his/her family; both are here thus labelled *ill*'' (Kleinman, 1980:73).

Illness and disease do not stand in a one-to-one relationship and should not be regarded as separate entities[29] (Eisenberg 1977:11). Both concepts are

---

causal agent with the aid of magic bullets, notably chemical drugs administered by highly trained experts who monopolise the knowledge and practice of medicine".

[29] When, for example, a disease is extreme, signaling the terminal stages, its pervasiveness makes illness inevitable. However, disease may occur in the absence of illness: the person with HIV may be asymptomatic and therefore unconcerned when the physician who measures his/her viral load and CD4 count becomes alarmed; s/he may stop taking prescribed medication because it makes him/her ill, even though s/he is told it will mitigate his/her viral load and also that it increases his/her CD4 count. Only when the HIV gives rise to AIDS will the person become a patient and agree with his/her doctor that s/he is sick. Even then the agreement may be limited to a common perception that a problem exists, which each is likely to formulate in quite different terms.

explanatory models mirroring multilevel relations between separate aspects of a complex, fluid, total health phenomenon. For patients, illness-related problems are usually viewed as constituting the entire disorder. Conversely, doctors often disregard illness problems, because they look upon disease as the disorder. Both views, however, can be regarded as insufficient. On the one hand, biomedicine is primarily interested in the recognition and treatment of disease (curing), and so paramount is this orientation that the professional training of health care providers tends to disregard illness and its treatment[30]. Biomedicine, according to Kleinman *et al.* (1978:252), ‘’has increasingly banished illness as a legitimate object of clinical concern’’. The systematic inattention to illness is, according to Kleinman *et al.* (1978:252), ‘’partly responsible for patients’ non-compliance, dissatisfaction with professional health care, and moreover for inadequate clinical care’’. This may also be a determinant of the increasing resort to an alternative healing system.

2.4.3 Sickness

The term *sickness*, according to Hardon *et al*. (1995:12), refers to the ‘’influence of society as a whole on illness and on the particular individual suffering from ill health’’. Sickness is thus related to a different phenomenon, namely the social role a person with illness takes or is given by society, which is often in the form of a stigma (Wikman *et al*., 2005:405).

Although the concepts of *illness*, *disease* and *sickness* are often thought to overlap, Wikman *et al*. (2005:450) argue that, in reality, things are not quite as simple. On the one hand, in some forms of experienced illness, the person often does not bother to have the conditions confirmed by a physician, either because the problem is too small and therefore s/he resorts to self-medication (*cf*. Abosede, 1984:699-703), or because there is not much help available. On the other hand, some illnesses and diseases in their initial stages (for example HIV-

---

[30] In this regard Eisenberg (1977:11) states quite flatly that “*a patient suffers illnesses, and doctors diagnose and treat disease”*.

infection) do not lead to sickness, because they do not result in an immediate reduction in community involvement and participation.

The meaning, in the literature, of this concept (sickness) is not clear with regard to its role in health and care. This study will equate it to the *sick role*[31], a concept arising from the work of the American sociologist, Talcott Parsons (1902–1979). Parsons, a structural functionalist, argued that social practices should be seen in terms of their function in maintaining order or structure in society. Thus Parsons was concerned with understanding how the sick person related to the whole social system, and with determining the person's function in that system. Ultimately, the sick role and sick-role behaviour could be seen as logical extensions of illness behaviour to complete integration into the medical care system. Parsons's argument is that sick-role behaviour accepts the symptomatology and diagnosis of the established medical care system, and thus allows the individual to adopt behaviours compliant with the expectations of the medical system. Basically, Parsons defined the *sick role* as having four main characteristics. First, the sick person is freed or exempted from carrying out normal social roles. The more severe the illness, the more one is freed from normal social roles. Everyone in society experiences this; for example, a minor chest cold 'allows' one to be excused from small obligations such as attending a social gathering. By contrast, a major heart attack 'allows' considerable time away from work and social obligations. Second, people in the sick role are not directly responsible for their plight. Third, the sick person needs to try to get well. The sick role is regarded as a temporary stage of deviance that should not be

---

[31] The complicated theoretical explanations of Parsons yielded a voluminous research literature in the second half of the 20th century, and they continue to stimulate much research today. In particular, there has been much study of the norms and values that define the behaviours of both the sick and those providing treatment. These studies form the basis of present-day research on the patient-physician relationship. They inform the various strategies adopted by behavioural scientists to intervene in this relationship to bring about positive behavioural changes in both patients and practitioners that will lead to better health outcomes.

prolonged if at all possible. Finally, in the sick role, the sick person or patient must seek competent help and cooperate with medical care to get well. This conceptual schema implies many reciprocal relations between the sick person (the patient), and the healer (the physician). In essence, the function of the physician is thus one of social control.

2.4.4 Treatment management

Since the early 1990s the strides made in the management of HIV and AIDS have steadfastly stuck to a *one-size-fits-all* strategy whereby practitioners involved maintain a single voice line with all treatment services. This strategy was primarily informed by the biomedical or clinical model. The reasons for this choice are underpinned by the biomedical logical inference that since disease is defined in terms of somatic parameters, physicians need not be concerned with socio-cultural issues that lie beyond medical responsibilities (Engel, 1977:129; Kleinman, 1980:53; Kleinman *et al*., 1978:251-258). These models uniformly treat clinical recommendations as unproblematic goals towards which patients should rationally strive. They do not question the underlying socio-cultural assumptions upon which the prescribed treatment regimens are based and evaluated. Instead, they only consider patients' concepts and actions, and treat the providers' concepts as a given, to which accommodation is required (Hunt & Arar, 2001:349). I am well aware that significant differences exist between the patient and the provider perspectives, which reflect their markedly different educational and socio-economic backgrounds. However, the predominant emphasis in clinical approaches to understanding the socio-cultural dimensions of illness management generally foregrounds how patients interpret and value clinical information and behavioural instructions.

This study argues that treatment behaviours may be much better understood if they are recognised to require an interplay between equal realms: that of the clinic and that of the patient's everyday life. Kleinman *et al*. (1978:253) argue that doctor-patient interactions are, in essence, transactions between the biomedical voice of a physician and the life-world voice of patients. They further point out the polarising effect of physician-patient dialogue, which obscures the fact that the multiple nature of both the patient perspective and the physician perspective, is more obvious in other contexts. Similarly, Cohen *et al*. (1994:61) found that, while patients emphasise difficulties in the social domain and the impact of chronic illness on their lives, providers see chronic disease and its management as fundamentally a pathophysiological problem, and are thus most concerned with technical control of the condition.

Anthropologists and other social scientists have taken up the challenge of understanding how differences between the provider perspective and the patient perspective may substantially influence health care interactions and treatment outcomes. Anthropologists, in their seminal studies on the patient's illness perception, have shown that patients' socio-cultural contexts are necessary additions to the treatment criteria used by health providers (Kleinman, 1980:104; 1988:121; Nanda & Warms, 2002:138). These aforementioned authors argue that during the health care encounter, patients and practitioners may be working with different and competing narratives of illness and disease management/treatment, informed by the individuals' unique socio-cultural backgrounds. While health practitioners draw from their professional training, patients' perspectives, notes Helman (2000:101), are based on different premises, employ different systems of proof, and assess the efficacy of treatment in different ways. The interaction between the narratives of patients and practitioners is a central component of health care, and, if not properly managed, such divergent and incongruent views may result in ineffective clinical outcomes (*cf*. Jones *et al.* 1998).

The work of Reynolds *et al*. (2004:144-147) on health beliefs has spawned numerous studies on medication adherence. Starting with the idea that patients' beliefs about medications will impact on how they take these medications, their work predicts that patients' beliefs concerning the likely outcomes of their conditions - with and without treatment - will affect adherence. Social factors influence health beliefs and behaviour both positively and negatively. Some factors function as barriers to seeking care, while others act as motivators or facilitators. The patient who has decided to consult a physician brings with him/her a unique view/perspective of such illness. This illness experience includes four dimensions[32]: the patient's health beliefs about what is wrong (an explanatory model or attribution of the symptoms); his/her concerns or fears (of specific disease or complications); the effects of illness on his/her daily functioning; and, his/her expectations of what should be done.

The perceived seriousness and perceived barriers motivate individuals to participate voluntarily in health behaviours and to seek health care for morbid conditions. *Perceived seriousness* refers to the perceived harmful consequences of a given illness in terms not only of physical and psychological health, but also societal roles (Rosenstock, 1990:40). Perceived barriers focus on the negative components of the anticipated action. Application of these beliefs has shown that they do not perform equally well in predicting health actions across all settings (Al-Hassan & Omran, 2005:14).

2.4.5 Health care

The genius of contemporary scientific medicine (biomedical approach) lies in the notion that a specific disease requires specific treatment. One consequence of this idea has been the historical shift in the way biomedically trained doctors practise: they have come to see themselves as 'treating disease' (perhaps even fighting disease), rather than 'treating the patient' (treating the 'whole person') (*cf*. Helman, 2000; Kleinman, 1980; Kleinman, 1987; Kleinman *et al.,* 1978; Moerman, 1979).

The meaning of the term *health* varies across cultures, and mostly entails more than merely the absence of disease: in some cultural contexts it is understood as

---

[32] Adapted for the purpose of the study from Kleiman's (1980:104) five major questions that explanatory models seek to explain for illness episodes.

a balanced relationship between people, nature and the supernatural. The study of what, in each context, is considered to be the absence of disease or the state of positive wellbeing - whether physical, psychological, or both - involves not only the study of definitions and theories of disease, but also that of all those cultural and social conditions and elements that contribute to the concept of the person and his/her development and relationship to the world and to others (ethnomedical approach) (Seymour-Smith, 1996:135). The dichotomy is reflected in the contrast between ‘healing’ and ‘curing’, with the former describing the resolution of the subjective experience of illness, while *curing* refers to the strategies applied to overcome the disease (*cf.* 2.4.2). *Health care* refers to the prevention, treatment and management of illness and the preservation of health through services offered by medical, complementary and alternative medicines (*cf*. Hardon *et al*., 1995; Van Rensburg, 2004; Herselman, 2007).

2.4.6 Diagnosis

‘’Important differences between biomedicine and African indigenous health care are found in their nature, purpose and methods of diagnosis. On the one hand, following the aforementioned disease/illness dichotomy, physicians attempt, through physical examination, to determine the disease process that has caused the symptoms, while making use of sophisticated techniques and evaluations of health in terms of physical and biochemical criteria, such as blood pressure, pulse rates, blood tests, etc. A person is considered healthy if measurements fall within the ranges regarded as *normal*. An African indigenous system of diagnosis, on the other hand, primarily aims to establish the cause of an illness and not the disease process. This is usually done by a diviner through divination procedures - such as bone-throwing or trance divination to interpret the will of the ancestors, or to determine and pronounce whether a condition is a consequence of witchcraft or sorcery’’ (Herselman, 2007:64).

2.5 RECONCILING PROFESSIONAL AND COMMUNITY INTERESTS

After first outlining the theoretical frameworks employed, and clarifying concepts, this dissertation has explored global approaches to HIV, AIDS and ARV treatment and how these are implemented at national and local levels. Although global frameworks are biomedically sound, these have until now largely failed to deal with social aspects of disease. However, the World Health Organization is increasingly advocating a context-related approach. According to Zumla and Gandy (2003:237), failure to rid the world of HIV is the failure of an exclusively biomedical approach. What is equally important is that the global community has failed to be committed to social justice. It is thus clear that HIV and AIDS cannot be solved in a biomedical context alone. The failure, therefore, does not lie solely with biomedicine, but also with the social, cultural, political and economic order in the world in which we live. Surmounting this challenge in South Africa demands a government committed to clamping down on corruption and mismanagement, while at the same time increasing both its commitment and its funding towards social and economic policies. This study acknowledges, with some reservation - given the gap that exists between policies and implementation - the recent pronouncement by the government of the day of its commitment to addressing challenges identified since the roll-out of ARVs.

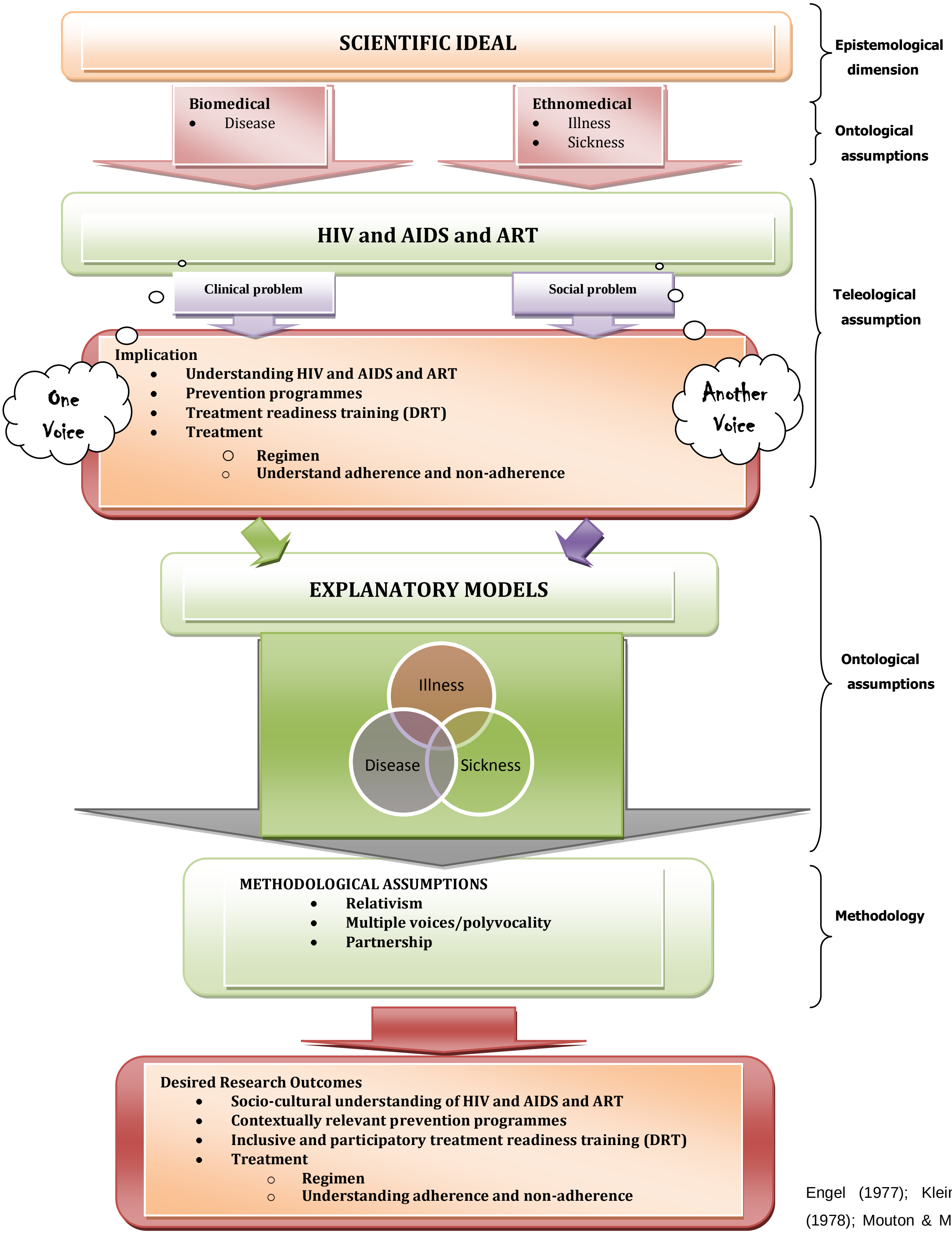
This dissertation has argued that HIV is a disease with a strong social dimension: a symptom of a larger social ‘ill’. In light of the above, various approaches to studying and applying medical anthropology – in an attempt to understand the connections between the micro and the macro levels in the epidemiology and aetiology of HIV, AIDS and ARV treatment - are indicated. The importance of including macro-level forces in anthropological micro-level analysis is emphasised. It is argued that a combination of applied biomedical and ethnomedical, rather than an opposition between these, is the most appropriate and useful approach to adopt.

The call for greater recognition of the role of socio-cultural and psycho-social factors in medicine is not new. Engel (1977), 33 years ago, published an article calling for an expansion of the biomedical approach to a biopsychosocial approach. The said article was followed by Kleinman's influential book, *Patients and healers in a context of culture,* published in 1980, which among other things calls for ethno-medical approach to understanding health problems and treatment. However, despite such calls, more recent studies suggest that socio-cultural and psycho-social factors continue either to be overlooked or are frequently missed in clinical encounters (*cf*. Astin, 1998; Marvel, 1993), and tend still to be underemphasised in medical education (*cf*. Tresolini, Shugars & Lee, 1995). Until recently, the dominant model employed in investigating HIV, AIDS and ART has been the biomedical model, which has created little space for alternative voices. The biomedical reluctance to create space for other voices stems from the logical inference that, since disease is defined in terms of somatic parameters, physicians need not be concerned with psycho-social issues lying outside the sphere of medicine. In the tradition of ethnomedicine, these studies classically address those beliefs and practices relating to disease that are products of indigenous cultural development and moreover not explicitly derived from the conceptual framework of modern medicine (Engel, 1977:129; Ho, 2004:753-756; Kleinman, 1980:53; Kleinman *et al*., 1978:251-258). Espousing the above view, this study proposes an ontological model to close the gap between ethnomedical and biomedical approaches to the study of health care, in general, and HIV, AIDS and ARV treatment in particular.

In many anthropological studies investigating the cultural aspects of disease, lay beliefs about illness are often juxtaposed with biomedical knowledge about disease. The former are viewed as culturally derived, while the latter represent objective reality (Ho, 2004:754). Implicit in this argument is the premise that, while the biomedical model constitutes a sound framework within which to understand and treat disease, the outline presented in Figure 6, argues that HIV, AIDS and ART adherence cannot be studied and understood without taking into account individuals' socio-cultural constructions of reality (situated within and constrained by the social context), and also how individuals construct an understanding of and impose meaning on the world around them. Employing three integrated methodological assumptions (illustrated by Figure 6), viz. (1) relativism, (2) recognition of multiple voices, and (3) partnership approaches, will facilitate the process of better understanding the interplay between the biomedical and the ethnomedical explanatory model in order to reconcile the two approaches (biomedical and ethnomedical), so that from being competing practices, they are transformed into complementary practices.

At the top of Figure 6, divergence between the two basic orienting perspectives, i.e., the clinical world view of the health care providers and the life world view of the patients are represented by the lack of overlap between them. Moving slightly down the figure, we see an uninterrupted divergent understanding of HIV and AIDS. For health care providers HIV and AIDS is a clinical problem, while for patients it is a social problem. The arrows linking the ‘voices’ indicate the dynamic process facilitated by the explanatory model. Through multiple clinical encounters, both parties come to share relatively similar notions of the nature of the dysfunction and what needs to be done to correct or control it. A convergence of these polarised views is facilitated by the explanatory model that creates space for dialogue between providers and patients regarding the nature of HIV and AIDS, and about what should be done to manage it. Nonetheless, although their perspectives may converge on key issues, they may still diverge in other important ways. Even when the patients and health care providers share concepts of the nature, cause and course of the illness, differences between the clinical perspectives of the care providers and the life-world perspectives of patients remain important in respect of how treatment behaviours are enacted and interpreted.

Figure 6: Reconciling professional and community interests



SCIENTIFIC IDEAL

Biomedical
- Disease

Ethnomedical
- Illness
- Sickness

HIV and AIDS and ART

Clinical problem

Social problem

Implication
- **Understanding HIV and AIDS and ART**
- **Prevention programmes**
- **Treatment readiness training (DRT)**
- **Treatment**
    - **Regimen**
    - **Understand adherence and non-adherence**

EXPLANATORY MODELS

METHODOLOGICAL ASSUMPTIONS
- **Relativism**
- **Multiple voices/polyvocality**
- **Partnership**

Desired Research Outcomes
- **Socio-cultural understanding of HIV and AIDS and ART**
- **Contextually relevant prevention programmes**
- **Inclusive and participatory treatment readiness training (DRT)**
- **Treatment**
    - **Regimen**
    - **Understanding adherence and non-adherence**

Engel (1977); Kleinman *et al.* (1978); Mouton & Marais (1988); Kleinman (1980)

2.6 CONCLUSION

In this chapter it was argued that we will never completely understand how to treat illness effectively unless, that is, we understand the socio-cultural context in which people live, fall ill and are treated. The discussion has focused on the need for a holistic approach to the study of illness-related behaviour among members of a multicultural society such as South Africa. A holistic approach represents an essential first step towards satisfying the need to integrate social and cultural dynamics in the planning and management of ill health. Illness and care are significant events for people everywhere. Anthropological evidence from both industrialised and developing countries indicates that illness is not, nor should always be interpreted exclusively in biological terms. Instead, a combination of biological, social, ecological and cultural explanations should be used to explain illness and care, in general, and, specifically, HIV and AIDS, and also the processes of their transmission, and their treatment. How people understand the cause of illness and its treatment, how they interpret their condition, and what resources they marshal to cope with these events, are thus, unsurprisingly, extremely important parts of culture. Without appropriate information, the development of effective interventions aimed at improving adherence to both ARV treatment and adherence to health care appointments among susceptible patients would be problematic. The suggested ontological model is informed by this study argument that advocates a collaborative approach involving the patients, the community, the health workers and the policy-makers, and focuses on means of addressing environmental and structural constraints in any effort to improve adherence both to clinical appointments and treatments.

CHAPTER 3: CONTEXTUAL UNDERSTANDING OF ILLNESS AND HEALTH CARE

3.1 INTRODUCTION

It is increasingly being recognised that contextually relevant HIV and AIDS understanding, prevention and mitigation are more likely to succeed than are enforced generic strategies (Thomas, 2008:228). However, little attention has as yet been devoted to understanding the way in which localised, affected individuals and communities themselves perceive, make sense of and subsequently experience the epidemic. While acknowledging the strides made by anthropology in addressing this backlog (Parker, 2001:163), recent commentary has suggested that there is still a relative shortage of information regarding perceptions on, interpretation of and discourse on HIV and AIDS (Barnett, 2004:1-2), and that research thus continues to focus narrowly on the objective and visible impacts of the epidemic, despite the key role of such understanding in the development of effective prevention and mitigation interventions (Nanda & Warms, 2002:138). This is especially true because HIV and AIDS are not only unique from a biological point of view but also as socio-cultural phenomena (*cf*. Bernstein & Van Rooyen, 1994). Their spread, especially, is clearly linked to particular patterns of human behaviour, especially sexual behaviour (*cf*. Kleinman, 1987:448). As such, Helman (2000:235) maintains that any attempt at understanding HIV and AIDS, controlling their spread, and their treatment cannot only focus on the search for a vaccine, or a pharmacological cure. The complex social and cultural environments in which the disease is embedded must decidedly also be taken into account. This may either help or hinder treatment adherence. It is argued that taking factors of patients' socio-cultural context into account - particularly in the context of treatment, care and support for the HIV-infected – is crucial for effective health service with a view to successful treatment outcomes and, ultimately, patients' improved quality of life.

As anthropologists have established themselves as integral contributors to the field of health research, one of their important roles has been to help explicate the patient's understanding of health for a clinical audience. This work often focuses on the management of chronic conditions, such as diabetes, stroke, epilepsy, HIV and AIDS (Cohen *et al*., 1994:60; Conrad, 1985:30; Okello & Ekblad, 2006:290), conditions the management of which requires ongoing modification of patient behaviours. While the clinical literature is at the centre of technical and physiological chronic-disease management, ethno-medical literature is assigning increased importance to understanding the social and cultural dimensions of illness (*cf*. Engel, 1977; Hahn, 1995; Kleinman, 1980; Kleinman *et al.,* 1978). This is an area where anthropologists are making important contributions. However, during clinical encounters, equal consideration is seldom given to the role of health-care-provider perspectives and patient perspectives. Such clinical practice commonly problematises only the patient viewpoint, while treating the provider perspective as an unquestionable point of departure.

According Hunt and Arar (2001:348) ‘’the research of anthropologists and other social scientists - whose focus is intentionally neutral and holistic - can bring important insights to such research by revealing both the limits of the clinical perspective and the legitimacy of the patient perspective, even when it is different from that of the health care provider’’. Furthermore they are of the view that ‘’exploring the articulation between patients’ and health care providers’ assumptions, and their expectations and perceptions - without giving primacy to or presuming the prior legitimacy of either one - is critical. It is also identified as an area of health research to which the unique perspective of anthropology seems especially well suited’’ (Hunt & Arar, 2001:348-351).

Against the backdrop of the above, this chapter overviews the underlying reasoning, illness understanding and narratives with a view to understanding how patients deal with seemingly conflicting biological and social theories about HIV, AIDS disease and ARV treatment The chapter also elucidates the cosmological assumptions that shape the perceptions of patients, particularly those regarding the notions of cause and effect. Furthermore, the chapter provides clarity in respect of sectors of health care, reflects on the socio-cultural context that informs choice of healer, and determines the dominant contextual factors that either facilitate or act as barriers to treatment adherence or non-adherence. Finally, a few concluding comments are made.

3.2 COMMUNITY AND ITS SOCIAL SYSTEM

This study reiterates the call made by Loams to acknowledge the influence of social system in community to the health of its members. In the words of Lomans (1998:1181), ‘’when John Snow removed the handle from the parish pump to *cure* an epidemic of cholera he was one of the first to practise what we now call healthy public policy. He was emphasising the importance of specific structural elements in the community to the health of its members. In this case it was the physical rather than the social structure of the community, but this illustrates that the basic idea of seeing the community and the individual as major foci of public health was well-established before the end of the 19th century. Nevertheless, in our haste to *privatise*, *rationalise*, *marketise* and *individualise*, we now seem to spend more time calculating how to apply medical innovations to the individual’s ill health than we spend evaluating or applying the discoveries of social science to the community’s well-being’’.

In the health context, according to Loams (1998:1182) ‘’the social system in a community consists of at least three elements: physical structure, social structure and social cohesion. A community’s physical structure (such as Snow’s village pump or, today, the design of a suburban housing development) does not only have direct influences on health through exposure to risks, but also indirect effects through either creating or neglecting to create health-inducing environments. Social structure in a community is rejected in things such as its meeting places, the mechanisms for income redistribution and the opportunities provided for exchange and interaction. This, again, has both direct and indirect effects on health: the direct effects ensure the availability of the basic prerequisites for health; the indirect effects facilitate collective problem solving or collective identity. Finally, social cohesion is very much a product of the adequacy of physical and social structure in a community. Along with aspects such as the cultural or social homogeneity of a community, its physical and social structure can either encourage or discourage mutual support and caring, self-esteem and a sense of belonging, and, enriched social relationships. All of these have been shown - largely by social scientists - to have an influence on the health of a community's members''.

3.3 AETIOLOGICAL VIEWS ON HIV AND AIDS

In order to understand how households and communities respond to HIV and AIDS, it is important first to appreciate how the locals understand these conditions. In this regard it is interesting to observe that - despite more than ten years' public information about the causes of HIV and AIDS, the modes of transmission, and the steps that can be taken to prevent infection - a range of more popular perceptions continues to prevail in the villages where fieldwork was conducted. These beliefs include ideas about the causes of AIDS - the disease of the moment - and its links to perceived promiscuity.

All societies have health care systems comprising beliefs, customs, specialists and practices aimed at diagnosing, preventing and curing illness in order to ensure good health (Mabunda, 2001:12). Within societies, according to De Villiers (1993:9), the value of biomedicine is often widely accepted, but not necessarily to the exclusion of traditional or non-conventional remedies. The absence of a generally shared perception regarding the causes of HIV and AIDS is reflected in wider varieties which have been used in the understanding, treatment and management of HIV and AIDS. Medical providers face the challenges of caring for patients from different cultures who speak different languages, display various levels of acculturation and have unique ways of understanding illness and health care.

For the fact that life is beset with ill health, it is a common practice for western-trained practitioners to seek explanations of disease in terms of causative laws that are related to concepts such as germ theory and fungal infection (Pretorius, 2004:535). In Foster's view (1978:778), the naturalistic[33] aetiological views are limited mainly to diseases, and draw from the biomedical approach in attempting to understand their underlying causes. The question as to '*why*' a particular person suffers illness is not always answered by biomedical science (Herselman, 2007:62). While the concept of *chance* is applied in western thinking, the traditional African world view makes little or no provision for either *chance* or *accident*. Within the latter world view, illness is ascribed to the active, purposeful intervention of an agent, which could be human (a witch), non-human (a spirit) or supernatural (powerful being) (Hammond-Tooke, 1989:83). Foster (1976:773-775) terms this mode of explanation 'personalistic'. In societies where such aetiological views prevail, the deities (witches and spirits) who send disease also cause contaminated relationships (Hammond-Tooke, 1989:83). According to Hammond-Tooke (1989:83) and Green (1999:12), 'personalistic' explanations of illness causation are informed by three stages (*cf*. Pretorius 2004:535):

- An '*immediate cause*' explains what was done to the person and what was used;
- An '*efficient cause*' explains who did it or what it did to the person; and
- *An 'ultimate cause*' explains why it happened to this specific person at this specific juncture.

Levels of causality explanation, understanding and treatment in the personalistic systems are not as obvious as with the naturalistic theories. A personalistic system has, in the views of Foster (1976:775-776), Pretorius (2004:535) and Thomas (2008:228), multiple levels of causality, and this system thus requires healers with supernatural and magical skills, because the patient is interested not only in the immediate ill health, but also wants to know 'what', 'why' and 'who' caused ill health. Patients, adhering to the naturalistic system of the cause of HIV

---

[33] A naturalistic approach describes disease by attributing it to the malfunctioning of some organ, and the disease is usually described by referring to that organ (Foster, 1976:775; Pretorius, 2004:534).

and AIDS, would, for example, accept a virological explanation that answers *how* the virus works, whereas patients opting for personalistic aetiology would not accept it as the only explanation because it may not prove to be an adequate explanation of *why* an individual has become infected with the virus. They would want to identify agents or sources that have sent the illness or have caused the illness to happen (Hammond-Tooke, 1989:32; Mabunda, 2001:12; Thomas, 2008:228). To further clarify the embedded nature of the personalistic theories of understanding ill health, natural/unnatural beliefs and pollution beliefs are discussed in the following section.

3.3.1 'Natural/unnatural' beliefs

An important point in understanding the role of culture is that it must always be seen in its particular context. This context is made up of cultural, historical, social, political and geographic elements (Nanda & Warms, 2002:138). Depending on the context, how many black people from rural settings experience their world is reflected in their use of the terms 'natural' and 'unnatural'. All events, including illness, may be classified along these lines. It is a perception of reality inextricably bound up with religious belief, so that 'natural' versus 'unnatural' is closely allied with 'good' versus 'evil' or 'godly' versus 'ungodly'. Natural events take place in the world as God made it and as He intended it to be. In health terms, one must take care not only of the body but also of the soul. 'Natural' illnesses in a system of this nature may be caused either by failure to take care of the body or by sinful behaviour. Such ideas are not foreign to physicians, though 'sin' may not appear as an objective cue in the patient's problem-oriented medical record (Snow, 1983:821). In Herselman's view (2007:63), ''natural causation produces an experience that can be explained as a process of cause and effect. Biological deterioration associated with ageing and the influence, on health, of environmental conditions - such as excessive heat or cold - are natural causes. If a condition worsens, recurs or becomes chronic despite it's having been treated, a patient's interpretation of such illness changes.

‘Natural’ causes are now replaced by ‘unnatural’ causes, and the responsible agent must be identified’’.

‘Unnatural’ events, reside, according to Snow (1983:822), outside the world of nature and do not follow natural laws. ‘Unnatural’ health belief systems make provision for the idea that ill health has been caused deliberately, and thus a supernatural or mystical cause is sought. By extension, ‘unnatural’ events are sometimes seen as the work of the Devil. ‘Unnatural’ events are frightening because by definition they are not amenable to the rules governing everyday life. ‘Unnatural’ occurrences are based on the belief that there are persons with extraordinary powers who are able to change the course of ‘natural’ events; a power that the said persons may use for their own ends or hire out: if the result of their machinations is an illness, it is an illness no physician can cure. Such ideas may indeed be foreign to physicians, who may view patients with such beliefs as deserving psychiatric consultation. ‘Unnatural’ occurrences/events are more readily understood if viewed as a metaphor for a deep and abiding mistrust of others, or as a belief that, given the chance, everyone will seek their own advantage (*cf*. Herselman, 2007).

3.3.2 Pollution beliefs

According to Hammond-Tooke (1989:50) ‘’Pollution beliefs fall into an entirely different category of witchcraft (. Some forms of illness and malaise are caused, not by the wrath of ancestors or the machinations of witches, but because people find themselves, often inadvertently, in a state of ritual impurity’’. Examples include widows and women who have either had an abortion or miscarriage, or are menstruating. These people are believed to be polluted, and such pollutants tend to be found within bodily fluids, such as blood and semen (Hammond-Tooke, 1989:50, 91; Ngubane, 1977:77). ‘’Ritually impure people are vulnerable to misfortune and must be avoided. Contact with pollutants through the breaking of taboos is considered to be both a cause and an explanation of illness. As avoidance of contact with such pollutants is not always possible, adherence to stringent moral codes and protective rituals are considered necessary so that people may attempt both to defend themselves and to restore order’’ (Thomas, 2008:235). However, changes regarding behaviour and expectations, particularly among young people, compromise their ability and willingness to adhere to such moral codes and rituals. They consequently make themselves vulnerable to contracting illness.

The above discussion points to the fact that a distinction can be drawn between these notions as sets of explanatory concepts that form part of the culture of people, and the private views of the individual, who draw on this range of theories/standpoints in an attempt to make sense of their lives. The sets of explanatory theories described above represent traditional world views of the Bantu-speaking peoples of Southern Africa. These theories have been passed on from one generation to the next. Together they form a unique, powerful system that explains the problems by which humans are beset. But these societies and cultures have for many generations been subjected to transition and are no longer either relatively integrated or comparatively unchanging communities. What we do however learn from the above is that the aspect of understanding what people ascribe the causes of illness to is an important addition to illness management. In accordance with the personalistic frame of reference, treatment comprises restoring harmony not only within the body, but also between the body and the environment.

3.3.3 Agents or sources of illness

In African societies, both natural and supernatural reasons/causes/instigators of illnesses are identified (De Villiers, 1985:49; Kriel, 1997:7). Supernatural causation views are seen as having little in common other than that they all rest on supernatural assumptions that modern medical science does not recognise as valid (Murdock, 1980:17). Such appraisals clearly bear the stamp of the outside observer and of an underlying ethnocentric assumption that modern medical science sets the standard by which other theories are assessed. Nevertheless, within this supernatural causation view, one needs clearly to determine what illnesses are ascribed to natural or to supernatural causes, since the remedies applied differ substantially and moreover have significant implications for treatment. Hammond-Tooke (1989:48) explains these views found among the South African Bantu-speakers as being attributable to three major influences on the human condition, namely “the ancestral spirits/ancestors, other people (witchcraft), and the supreme being (God who rarely seems to intercede in the affairs of man)”. These agents can, according to Hammond-Tooke (1989:57), cause serious illness. The notion of illness (*ho kula*) encompasses physical illness together with misfortune and imbalances. Thus, anything that brings one into disharmony, be it with the environment or others, can be perceived as potentially illness-/disease-causing. The discussion that follows provides an overview of the perceptions that shape Bantu-speakers’ understanding of the causes of illness.

3.3.3.1 Ancestral spirits/ancestors

Generally, among the Southern Bantu-speakers who still subscribe to this ideology, the spirits of deceased ancestors are frequently held responsible for sending illness, because the living have erred in some way. Here, illness is ascribed to the direct actions of supernatural entities, such as gods or ancestral spirits (*badimo)*. The ancestral spirits are those spirits important to each individual within the patrilineage. The lineage head, and also the various family heads, play the role of intermediaries between these family spirits and each member of the patrilineage. The family spirits of the head of the household are approached for help in the event of illness (*cf*. 3.4 sectors of health care). In the Bantu-speaking people’s view, the ancestral spirits normally reside happily and peacefully in the abode of the ancestral world. They can, under circumstances and for certain reasons, however, leave this existential world to visit the living. When the living do not respect the spirits and do not care for them by means of sacrifices, and when the living fail to obey the commands of the spirits and fail to maintain/honour the prescribed customs and rules of life, the spirits become unhappy and could send illness or misfortune (Hammond-Tooke 1989:47). On this basis, neither home remedies nor a physician are considered useful in treating the condition. The above circumstance renders patients' socio-cultural beliefs about health and illness an important matter in the study and understanding of treatment adherence/non-adherence.

3.3.3.2 Witches

Liddell *et al.* (2005:695) maintain that the many characteristics of HIV and AIDS make witchcraft a likely attribution for this disease complex. For this reason, it is necessary to pay closer attention to the phenomenon of witches. Blaming other people for one's ill health is a common feature of smaller-scale societies in which interpersonal conflicts are frequent. First in line are witches. Witchcraft refers to the practices of persons with malicious intent to cause harm through the use of harmful substances and invisible supernatural forces (Ferraro, 2001:304; Hammond-Tooke, 1989:48; Haviland, 1999:400). Witchcraft is often associated with *sejeso* (food that has been drugged to do a person harm), or the malicious manipulation of herbs and other substances, believed to cause a wide variety of misfortunes ranging from unemployment and interpersonal discord to illness and death (Thomas, 2008:24).

3.3.3.3 Supreme being

The Supreme Being (commonly known as *Modimo* in Sesotho, *Nkulunkulu* in isiZulu, *Xamatha* in isiXhosa) is also regarded as an agent of illness. Natural phenomena such as minor illness or affliction relating to changes in the seasons and diseases that take on epidemic proportions are associated with the Supreme Being (Ngubane, 1977:23). In these instances, the Supreme Being is named as the sender of illness when no other agent of disease can be identified (*cf*. Kriel, 1997). This explanation of ill health draws on the religious interpretation of illness that endorses the notion of illness as a self-inflicted punishment for culturally unacceptable behaviour (*cf*. Thomas, 2008). When the cause of ill health is attributed to moral deviance, the resulting illness is stigmatised[34] and serves to marginalise an already weakened pool of sufferers and their families (Alonzo & Reynolds, 1995:303,305; Sontag, 1983:103).

The 'civilising' agendas of both the colonial and the apartheid regimes viewed any beliefs and practices associated with ancestors and witchcraft as irrational and primitive, and thus forbidden. Education based on western science and Christianity was viewed as a necessary prerequisite for ameliorating and replacing backward, uneducated notions of witchcraft. However, recent research done by Thomas (2008) among the people of the Caprivi in Namibia calls attention to the strong associations between beliefs in ancestors, witchcraft and the Supreme Being on the one hand, and illness prevalence, on the other. Although illness caused by witchcraft can manifest in a variety of forms, symptoms are often similar to those associated with HIV and AIDS (*cf*. Liddell *et al.,* 2005). Obviously, a dual taxonomy for phenomena as complex as world view beliefs about the causes of illness leaves many loose ends. It should however be remembered that a taxonomy is not an end in itself, something to be polished and admired; its value lies rather in the understanding - that it makes possible - of relationships between apparently diverse phenomena, throwing into sharp perspective correlations in health institutions and health behaviour that tend to be overlooked in descriptive accounts (*cf*. Garro, 1986).

Because the aetiological view was here adopted, the focus in this study fell on discovering the nature of the cultural knowledge brought specifically to the occurrence of ill health, how such knowledge is applied in evaluating illness, and

---

[34] Stigma is a social construction which dramatically affects the life experiences of the individuals infected with HIV and those affected by HIV, e.g. partners, family and friends. When speaking of stigma, Alonzo and Reynolds (1995:303) suggest it refers to the entire people who are regarded negatively, some for having violated rules, others just for being the sort of people they are, or having traits that are not highly valued. In general, stigma represents a construction of deviation from some moral ideal or social expectation, whether the ideal is for correct social behaviour or to be free of a disfiguring or fatal infectious disease.

what considerations are brought to bear in making treatment decisions, i.e., how illness forms part of these meaningful worlds. According to Garro (2000:307), cultural meanings are resources that may be variably drawn upon to help make sense of either one's own or another's experience. Thus, cultural understanding does not function in a top-down, deterministic manner, but is, rather, better seen as a vehicle (which might both enable and constrain interpretive possibilities) with which to navigate the ambiguity surrounding illness and other troubling experiences.

3.4 SECTORS OF HEALTH CARE

"Whenever an individual or set of individuals becomes ill or is confronted with overwhelming health problems, various maternal and paternal kinsmen and occasionally their friends and associates, rally for the purpose of sifting information, lending moral support, making decisions, and arranging details for therapeutic consultation'' (Janzen, 1978:4).

According to Herselman (2007:64) and De Villiers (1985:49), ''exposure to biomedicine does not mean either that traditional understanding of illness is rejected, or that beliefs and behaviour of a more conventional kind persist. The different health-seeking options available as a result of the co-existence of biomedicine and traditional medicine call into question those factors that influence someone's decision to consult a particular practitioner, and also what happens when a patient who maintains more traditional beliefs does indeed consult a western physician. As indicated, physicians are, by tradition, believed to be incapable of curing conditions with supernatural causes. Hence, on the basis of their interpretation of what ails them, people differentiate between conditions treated by western physicians and those requiring an indigenous healer's attention. It is important to note that this is not a fixed rule, nor is it universally recognised''.

Helman (1996:65) maintains that people who fall ill typically follow a hierarchy of resort, ranging from self-medication to consulting with others. Studies of the social context of care disclose three structural domains of health care in societies: professional (nurses and doctors), popular (family, social network and community) and folk (non-professional healers). Each domain possesses its own explanatory system, interaction settings and institutions (Kleinman, 1980:50-60). Consultation with all these sectors of health care, according to Herselman (2007:64) and De Villliers (1993:13) ''represents a strategy aimed at maximising chances of recovery. Other reasons for dual consultation are because patients want to know how best to cope and because they seek different approaches in respect of their conditions. A physician is consulted for medication to alleviate symptoms, while the indigenous healer identifies the cause and ensures that a condition does not recur (*cf*. personalistic theories of understanding ill health). As treatment by one practitioner may be too slow in yielding results, the patient then may consult another for treatment that yields more rapid results''. *Health care pluralism*[35] is not a new phenomenon. Pretorius (2004:11) maintains that, in most societies worldwide, there has always been the possibility of choice between different kinds of practitioners with different ways of explaining, diagnosing and treating health care. Although these therapeutic modes coexist, they are often based on entirely different premises and may originate in different cultures.

In no particular order, the following discussion provides an overview of the different health care sectors found in communities.

3.4.1 Popular (lay) health care

The popular sector of health care consists, according to Hardon *et al.* (1995:25), of the lay, non-professional, non-specialist, popular culture arena in which illness is first defined and health care activities later initiated (*cf.* Kleinman 1980:50). When illness occurs, for example, among the Sotho, the person reports it to those around him/her. Such persons are the ones who label the malady as being serious or not (Ngubane, 1977:101). The sector can be thought of as a matrix containing several levels, namely individual, family, social network, and

---

[35] Coexistence of a variety of healing traditions in a society (*cf.* Abosede, 1984; Pretorius, 2004)

community beliefs and activities (Kleinman, 1980:50). In this sector the patient's family, relatives, friends, and neighbours participate in the healing practice. They play the role of information provider, co-worker, and emotional supporter, and accompany the patient in the process of seeking treatment. They try to obtain information on the condition, what treatment is most effective, and where to obtain it. Among the options is self-treatment or self-medication. Self-treatment is based on lay beliefs about the structure and function of the body, and the origin and nature of illness. It includes a variety of substances - such as indigenous medicine or traditional folk remedies. People considered by family of the ill person as resourceful, for assistance and advice on matters of health, are those with long experience of a particular illness and also those with extensive experience of certain life events. Their credentials are mainly their own experience rather than education. In this sector the main arena of health care is the family. This health care is resorted to because it is generally believed to be good for the body and for social relations (Kleinman, 1980:50).

All aspects of this sector of health care may sometimes be harmful to people's physical health, especially those infected with HIV and AIDS. The family, for example, may either facilitate or impede health care. The family's response to sick members is, according to Helman (2000:67), an attempt to contain them, their sickness, and the social problems that such illness generates within the family circle rather than share it with an outsider, such as a medical practitioner.

3.4.2 Folk and/or traditional health care

Folk health care is provided by non-professional, non-bureaucratic specialists. This sector comprises a mixture of many different components. Some are closely related to the professional sector such, as folk herbal medicine; others are related to traditional practice (Kleinman, 1980:59). In Southern Africa, there are at least two broad types of traditional practitioners, namely herbalists and diviners. The diviners are called to their profession by their ancestors through sending of an illness syndrome, referred to as '*go thwasa*' (the Sesotho for a process of becoming a diviner) (Hammond-Tooke, 1989:106). To become a diviner, the initiate has first to be cured of the '*intwaso*' (spiritual possession) condition through a series of rituals, which include the use of techniques of divination and curing. This process involves the initiates being taught the ways of traditional healing by a practising healer.

Hammond-Tooke (1989:51) and Kleinman (1980:59) view the world of the religious health care subsector as mystical and magical. Healers have to see the unobservable world. The healing competency of the religious healer is based on powers of magic and mystique. Patients never rely on a healer until they see evidence of magic and mystique. Thus, the patient does not give any information about their physical condition or show their affected limb until the healer notes their condition. In this way the mystical power of the healer is tested. The healer must tell intuitively what physical problem the client is inflicted with. The diagnostic process seeks answers not only to the question of how the disease originated, but aims also to establish who or what caused the disease.

Once patients start trusting the healer's competency, they openly discuss physical problems, feelings and beliefs about their condition, and even their family problems. The religious healer approaches the problem holistically, dealing with all aspects of patients' lives, including their relationship with other people, with the natural environment, and with the supernatural and also their physical or emotional problems (Helman, 1996:69). Healers of this type, when faced with ill health, may employ a ritual of *divination*. There are many forms of these rituals worldwide. Specific to small-scale societies, these rituals entail, inter alia, the use of bones, special stones and tea leaves. The arrangement of these is closely examined by the healer for any evidence of an underlying pattern. Later, the healer informs the patient of the supernatural aetiology, and suggests healing strategies (*cf*. Hammond-Tooke, 1998:47). If the cause of ill health is believed to have been sent by the ancestors, its curing depends not only on medicines but also on rituals. The healer performs cleansing rituals (e.g. *ho* *phalatsa*[36], *ho peita*[37], *ho karubetsa*[38] and *ho kubetsa*[39]), sacrificial rituals (slaughtering a cow, a sheep or a goat and offering selected parts of the slaughtered animal as a sacrifice to the ancestor) and prepares a traditional mixture (commonly known as '*concoction*') for the patient to consume. Such rituals are believed to reconnect the living descendants with ancestors who might have been angered. Although this has no basis in fact, there has recently been a trend of linking HIV and AIDS with a condition of heat (*fisa*), thus with pollution. Indigenous healers are able to treat the pollution (*sefifi*), which might explain claims by such practitioners that they are in fact able to treat HIV and AIDS. In this study, traditional healers were often consulted by participants for ritual purposes, some of which could have been HIV related, and for general medicines both for strengthening the immune system and for combating "weak blood" – also important in order to deal with HIV and AIDS.

Despite, as noted above, patients being attracted to this particular health care sector by its mystique and magical character, Kleinman (1980:59) and Hardon *et al*. (1995:26) note a further advantage: the traditional practitioner-patient relationship is a good working relationship, because both parties embrace the same cultural values and the same world view as the communities in which they live, for example beliefs about the origins, significance and treatment of ill health.

---

[36] *Phalatsa/Kh'apha* entails a procedure being performed in the belief that it also cleanses the body, particularly of bile. The patient consumes much water, sometimes pure, but at other times infused with certain herbs, and then s/he forces him/herself to vomit the water.

[37] *Ho Peita* is a sort of physical cleansing of the body, whereby water is inserted through the anal orifice with the expectation that when it comes out, it will carry with it toxins and other unneeded materials that could be of harm to the patient's general health.

[38] *Arubela* this practice is believed to cure flu/cold. In this instance, a bowl of hot or boiling water, usually mixed with herbs, is placed on the floor, and the patient kneels in front of it covering him/herself with a blanket to inhale the steam. The sweat is believed to rid the body of fever and other symptoms associated with flu.

[39] *Kubetsa* entails burning herbs and letting the patient inhale the smoke or, alternatively burning herbs around the patient's living compound. The ritual is performed to cast away the evil spirits and curses.

In most cases they also share the same lingual background. Regardless of their many advantages, it is important, generally, not to over-romanticise folk healers. As with all other health care providers, their ranks may well also include healers who are incompetent, ignorant or greedy, or even those who have a reductionist view of ill health and how it should be treated. Furthermore, some of the techniques they use may also be very life-threatening to their patients (*cf.* Helman 1996).

3.4.3 Professional/conventional health care

The professional/western/conventional sector of health care comprises a conglomerate of organised healing professionals. In most societies, this simply means that they represent scientific medicine. Persons forming part of this sector are professional medical doctors, pharmacists, nurses and other paraprofessionals who are trained in a formal education course and certified by a national professional body (Kleinman, 1980:53). Diagnosis comprises a combination of information, including, also observation and patient self-diagnosis. Observation involves noting physical symptoms, while patient self-diagnosis entails the reporting of symptoms by patients. If deemed necessary, the impressions of other family members regarding the patient’s sickness may also be obtained. As Helman (1994:75) notes, ‘’in most countries, scientific medicine is the basis of the professional health care sector, but it is important to realise that, in rural areas, scientific medicine provides for only a small proportion of health care. Medical health care services are often scarce resources, with most health care occurring in the popular and folk spheres of care’’. World Health Organization statistics on the doctor:patient ratios for 2006 cite the huge variation in this ratio throughout Africa as one of the reasons for this mixed pattern. South Africa is recorded to have 77 doctors available per 100 000 people (WHO, 2006). These figures may have increased since their last recording; however, they probably overestimated the numbers of doctors actually directly involved in actual patient care, especially in public health institutions - as many work in private care, and in the research and administration spheres. In addition, the distribution of doctors is not uniform: in non-industrialised societies doctors tend to cluster in cities, where facilities are better and, as a result, leaving, especially rural communities to rely on the popular and folk sector of health care (*cf.* Helman, 1994:76).

In general, ill people move freely between sectors, often using all three sectors at once, especially when treatment in one sector fails to relieve physical discomfort immediately.

The coexistence of a variety of healing traditions in societies has, among other things, led to the continuous growth of alternative or complementary medicine. When faced with the apparent popularity of unconventional medical practices and with the fact that people (service providers) seem quite willing to accept alternative methods of payment (e.g. livestock, sometimes in pay-off) for their services, the question arises: What are the socio-cultural and personal factors (health status, health beliefs, attitude, motivation etc.) that underlie decisions to use complementary therapies? At present, there is no clear or consistent comprehensive theoretical model to account for the increasing use of complementary forms of health care. Accordingly, this section explores different authors’ views that might account for this phenomenon. The following discussion provides an overview of complementary medicine as a strategy used by local communities to restore health.

3.5 COMPLEMENTARY THERAPIES/MEDICINES[40]

When faced with illness, people are confronted by complex therapeutic choices that are based both on the types of healers available and on the particular explanatory model to which the sick person adheres. The patient's choice of system is determined not only by a patient's understanding of causation (thus the classification of the moral or spiritual aspects of the conditions), but also by what a particular health care system has to offer, and by the patient's personal circumstances. Treatment management involves a pattern of resort (doctor-shopping), selection and evaluation of medication, and support of the sufferer (Janzen, 1987:68). As Conrad (1985:32) has noted, patients have been seen as essentially passive receivers of advice and as people who are faced with obstacles in the form of their beliefs and their particular situations. More recently, however, patients have been viewed as actively making responsible decisions about therapy. These decisions are based not only on their knowledge of both the treatment regimen as such and how it might help their condition, but also on different priorities - their own and those of other people (Rosner, 2005:555). Regardless of the role assigned to patients (passive or active), it is clear that the full benefit of the many effective medications that are available will be achieved only if patients follow prescribed treatment regimens reasonably closely (Osterberg & Blaschke, 2005:487).

The one, particularly useful concept when examining decision making in respect of health seeking is that of *a therapy-managing group* (Janzen, 1978:4). The therapy-management group is a network of close kin, friends and associates who

---

[40] Today, many people use complementary medicines for a wide variety of diseases (Eisenberg *et al.*, 1998:1569). In this study, I use the term to refer to a group of diverse medical and health care systems, practices and products that, though they are not generally considered part of conventional medicine, are used together with standard medical care. A related concept, 'integrative medicine' is a total approach to care - one that involves the patient's mind, body and spirit (*cf.* Eisenberg *et al.*, 1993; Eisenberg *et al.*, 1998:1572; Hammond-Tooke, 1998).

manage, through moral support and information sifting, the therapy of the patient's illness (Janzen, 1978:4; 1987:68). The patient is at the centre of this network of people, such as family members, members of the patient's household, or co-workers who are also affected by the patient's illness. It has proven useful to extend this notion to include also health workers, in particular home-based carers who have a direct impact upon patients' experiences of being sick and upon attempts at getting them well.

According to Abosede (1984:700), almost all episodes of illness are at first self-treated, often within the family network. Home case-management practices include treatments (such as home remedies and administration of pharmaceuticals) administered inside the home. If this does not produce symptomatic relief, consultation is made with family members, neighbours, traditional healers, faith healers and/or western doctors (Foster, 1976:778; Hammond-Tooke, 1989:103). Janzen's model (1978:xviii) is useful for examining medical pluralism, where people rely on lay knowledge to 'diagnose' illness, to select and evaluate therapies by combining therapies from different medical systems. Kleinman (1980:182-186) sees treatment choice as the outcome of a sequence of transactions, for example, availability[41], accessibility and

---

[41] The availability of any service, according to Abosede (1984:702) and Pretorius (2004:547), can be viewed in two ways: availability in terms of the overall supply of the service and availability in terms of geographical distribution. Rural communities have historically had limited access to quality health care services, a concern noted in the Alma-Ata Declaration (1978:DII). Access to quality health care services meant having to wait too long until the next doctor's visit to the local clinic, or alternatively having to walk or travel long distances to receive health care services. In South Africa, more than a decade after the transition to democracy in 1994, questions are still being asked on how to improve access to decent health care services in rural communities (*cf.* Declaration of Alma-Ata, 1978:DV) This question is important, because availability of and access to quality health care services directly affect people's health. To people with poor health status and only limited access to a range of health care services, preventive treatment can be critical towards managing and preventing disease and improving quality of life.

affordability[42], and acceptability[43]. Other related factors noted by Ngubane (1977:101) and Abosede (1984:702) as influencing patients' choices of a healer are: patients' belief systems; the amount of money available; the perceived severity of the symptoms or the seriousness of the illness; availability of a particular health agency; and, assessment of the type of healer, based on age/gender.

Astin (1998:1548-1552), in his research on why patients use alternative medicine, draws our attention to factors such as dissatisfaction[44]; need for personal control[45] and philosophical congruence[46]. Regardless of the patient's

---

[42] Compared with the services of modern medical practitioners, those of traditional healers are exceptionally accessible, especially in rural communities. In the latter sector patients have the benefit of cultural, social and geographical proximity. The view of traditional medicine as being readily accessible often obscures the relative inaccessibility brought about by the limited number of clinics authorised for ARV rollout, which translates to the scarce availability associated with ARV treatment in the rural communities (*cf.* Pretorius, 2004:547). Traditional health care is often the only accessible source of health care, especially for the world's poorest patients (*cf.* Abosede, 1984:702).

[43] When a particular service is available, accessible and affordable, the prerequisite for its use is that it will be acceptable to the consumer. Because traditional medicine forms part of people's socio-cultural pattern of understanding and treating health problems, there is no doubt about acceptance and utilisation of traditional medicine by a large clientele in South Africa, and even more so in rural communities (*cf.* Pretorius, 2004:548; Declaration of Alma-Ata 1978:DIV).

[44] Patients' dissatisfaction with conventional treatment might be because it has been ineffective, has produced adverse effects or has been seen as impersonal and/or too costly (Astin, 1998:1548). This carries some truth, especially for the patients on ARV, who might want to see immediate relief, especially after a protracted illness, but also because of the side effects - especially to first-time users - of ARV treatment.

[45] According to Astin (1998:1548), patients seek alternative therapies because they see them as less authoritarian and more empowering and as offering them more personal autonomy and control over their health care decision. The Declaration of Alma-Ata "requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the

pattern of resort, it is clear that the full benefit of the many effective medications that are indeed available will be achieved only if patients follow prescribed treatment regimens reasonably closely - and even more so for ARV treatment (Ostenberg & Blaschke, 2005:487),usually measured by the patient's level of adherence (Orrell, 2005:172).

The following discussion provides an overview of the factors that act as facilitators or inhibitors both to clinical appointment and ARV treatment adherence.

3.6 ADHERENCE AND NON-ADHERENCE: CLINICAL APPOINTMENTS AND ART

The term 'adherence' has of late been preferred over 'compliance', because the latter term implies a difference in authority between the physician and the patient. The patient-practitioner relationship is hierarchical, one in which the curer expects compliance; however, the health-seeking explanation refers to a much broader range of interaction in attempting to cure or reduce the impact of the health problem (Myoung Ok Cho, 2004:155-156). Rosner (2005:557-558) suggests that adherence should not be defined exclusively in terms of medication use, but should include behavioural aspects of self-management, for example; appointment adherence (*cf*. De Reuck, 2008) and in other cases, lay consultants or indigenous healers may have been chosen by patients prior to seeking western treatment. Adherence has been noted by Reynolds *et al*. (2004:144) and Rosner (2005:557) as a problem in the management of any chronic disease. In HIV infection, consequences of poor adherence or non-adherence include not only lack of efficacy, but also development of resistance. Thus, adherence is a

---

ability of communities to participate". To the extent that this is lacking during the screening period, patients will seek alternative therapies.

[46] Alternative therapies, in this regard, are used because they are attractive because of their compatibility with the patients' values, world view, spiritually/religious philosophy, or beliefs regarding the nature and meaning of health and illness (*cf.* Abosede, 1984; Astin, 1998:1548; Ngubane, 1977).

critical issue in antiretroviral therapy (*cf.* Mehta, Moore & Graham, 1997; Reynolds *et al.,* 2004; Wainberg, Little & Currier, 1999).

Helman (2000:106) argues that, given the uniqueness of each patient's socio-cultural context, the methodological issues involved in gauging adherence are severe and contribute to the difficulties in reaching reliable generalisation. Marston (1970:320) found that when "demographic variables were examined separately, little or no association was found between adherence behaviour and sex, age, race, marital status, socio-economic status, or education" (*cf*. Meichenbaum & Turk, 1987). Other factors, such as psychological state or perceived severity, seem, similarly, to have been inconclusive.

The complexity of the subject is portrayed by Davis and Eichhorn (1963:249) in their findings about chronically ill patients. They note that more of those patients who reported high influence from family and friends initially complied with the doctor's regimen than did those who were only slightly influenced by family and friends. The importance of a holistic approach to adherence is supported by those adherence studies that focus on the quality of doctor-patient relationship communication, which may be a major variable influencing adherence (*cf*. Helman, 2000:103-105). This highly subjective measure is also the one that implies that the doctor has taken the time necessary to educate the patient, or that the two have congruent health and other beliefs.

Rather than attempt to review and critique the voluminous literature on patient adherence, I shall illustrate the general theoretical framework that I believe will be useful for understanding adherence and non-adherence within the individual socio-cultural context. Most research studies on adherence (*cf*. Christensen, 2000:435-442; Christensen & Johnson, 2002:94-97; Christensen & Smith, 1995:305-312) encourage the application of the patient-context interactive approach to understanding adherence. This is primarily because of the lack of consistency in previous adherence research, which might be interpreted as suggesting that patient characteristics do not play a predictable role in determining adherence behaviour (Christensen, 2000:435). The basic assumption of this framework is that factors that influence adherence can be better understood by considering the interactive effects of patients' characteristics of illness and medical treatment contexts. This study argues that it is the interactive effect of person factors and context factors that most strongly influences adherence outcome (to both medication and clinical appointment). This approach draws from the five-factor model of personality framework[47] (*cf*. Christensen & Smith, 1995:305-312).

From the perspective of this particular framework, variability in personality traits can be distilled to five underlying dimensions: *neuroticism* (reflecting generalised emotional distress or chronic negative effect); *extraversion* (reflecting sociability, assertiveness and cheerfulness); *openness to experience* (reflecting imaginative, intellectual curiosity and unconventionality); *agreeableness* (reflecting altruism); and *conscientiousness* (reflecting self-discipline or self-control, dependability and will to achieve). For example, *conscientiousness* may be the most accurate trait descriptor of those qualities of the individual thought to be important in terms of adherence behaviour (Christensen & Smith, 1995:306). Patients high on the *agreeableness* trait may respond better to group-based interventions (*cf.* culture and society, collectivism) or interperson-oriented strategies promoting adherence, whereas those low in this trait may benefit from an individualised, less confrontational approach (*cf*. culture and society, individualism) (Christensen & Johnson, 2002:96).

3.6.1 ADHERENCE TO CLINICAL APPOINTMENTS

Successful adherence to any medical care for ART, entails adhering not only to the treatment but also to related appointments with health care providers, be they to see the physician, for blood tests or for medication refills (Chesney *et al*.,

---

[47] The potential importance of the five-factor model of personality as an organising framework for patient assessment has been highlighted in both adherence (Wiebe & Chistensen, 1996) and psychotherapy (Anderson, 1998).

2000b:1602). Interest in developing strategies to address non-adherence has led to investigations of its correlate (Israelski *et al.,* 2001:472). For example, male gender seemed, in some studies, associated with decreased adherence, especially when associated with mental illness and age (Mehta *et al*., 1997:1666). Gender often reflects a number of conditions and should thus not be overlooked. In fact, the impact of gender on adherence relies heavily on the context and the social situations in which individuals interact. For example, it has been noticed that in some cases women were missing more doses and clinic visits than men (Ohmit *et al*., 1998). This difference could be explained by the fact that those particular women had to manage difficult family and child-care responsibilities. Indeed, when free, on-site childcare and other family care responsibilities were provided, adherence with scheduled visits would improve immediately (Kissinger *et al*., 1995:20; Mehta *et al*., 1997:1669). Although adhering to clinical appointments may, in itself, not be adequate to guarantee adherence to drug regimen, Israelski *et al.* (2001:470) argue that adherence to drug regimen is not possible without first attending to clinical appointments (*cf*. De Reuck, 2008). This study views attendance to clinical appointments as adherence-related behaviour (which is equally important in the case of adherence to drug regimen), as a behaviour which needs to be consistent over a prolonged period of time.

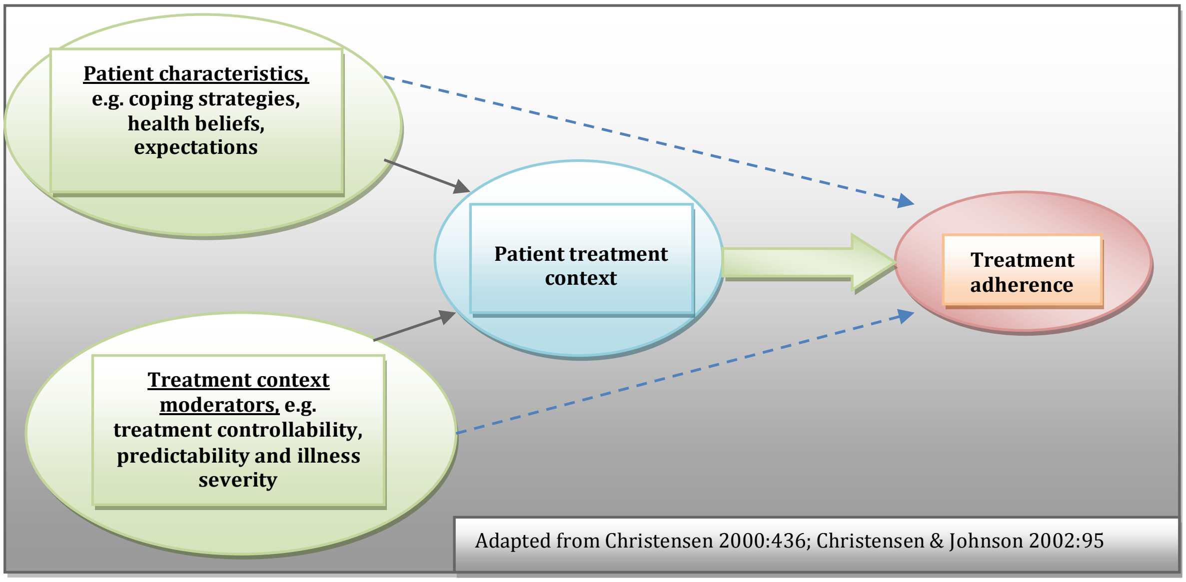
3.6.2 ADHERENCE TO ARV TREATMENT

As with most chronic illnesses, patient non-adherence to the prescribed medical treatment regimen is a pervasive problem among HIV and AIDS patients. Also, for many years, the reasons for non-adherence have been studied in the contexts of doctor-patient communication and popular beliefs about illness and treatment (*cf*. Rintamaki *et al*., 2006:362-366; Roberts; 2000:157-166). Most socio-behavioural research attempting to identify correlates of non-adherence to ART has been based on cross-sectional studies that have limited power to discriminate between baseline predictors and those factors that are related to the patient’s subjective experience during the course of treatment.

Adherence to ARV treatment is essential towards maintaining long-term health benefits and avoiding development of drug resistance. It is not possible for health providers to predict who will ultimately be adherent to his/her treatment plan, for, adherence, although not consistently across adherence research literature, does decidedly correlate with gender, cultural background, socio-economic status, family networks and relationships. To put the latter in context, Dimatteo and Hays (1981:136) maintain that interpersonal relationships cannot be validly analysed as though they consist of a set of isolated dyads in that each dyadic relationship is embedded within social networks that structure that particular relationship. These networks include family members, friends, neighbours, co-workers, governmental and non-governmental organisations, and others with whom an individual regularly interacts. Networks of actors are interdependent; events that impact on any individual have consequences that extend to the other network members.

The anthropological approach to gaining understanding of a certain topic is to study it in its context. It is therefore essential to provide all patients with a comprehensive plan to support adherence by utilising multiple strategies, all members of the health care team, the family and community. Recent research on ARV adherence indicates the following factors as major impediments to adherence: cultural traditions and traditional beliefs, poverty, and, the lack of food security. It is thus regarded as important for health providers to understand the socio-cultural context of the people who are on antiretroviral treatment before making decisions about their health care.

Figure 7: Conceptual representation of the patient-by-treatment-context interactive framework.



Adapted from Christensen 2000:436; Christensen & Johnson 2002:95

The dashed lines reflect the fact that research generally does not find that patient characteristics or contextual features have a significant effect on treatment adherence (*cf*. Christensen 2000:436; Christensen & Johnson 2002:95).

Recent data suggest that treating co-existent symptoms (particularly depression), ensuring that patients understand the regimens, developing individualised plans for integrating the regimens into daily activities, and enhancing communication with treatment staff, are potential ways of improving adherence (Rosner, 2005:555). Kleinman (1980:363) suggests the following:

- Treatment encompassing recognition of the influence of everyday life can be related to a higher degree of adherence.
- Emphasis on shared responsibility of the patient and physician in health outcomes can likewise result in better adherence.
- Apart from the quality of doctor-patient transactions, the degree of adherence is also enhanced by specific practitioner attention to

explanatory models, role constraints, and the views and influence of lay consultants.

In general, what is needed is an adherence system that is patient friendly, provider friendly, concise, and one that can be individualised for each patient. The simplest and most practical suggestion to physicians and those involved in patient therapy is to ask the patient non-judgementally how often doses were missed. Patients generally want to please their physicians and will often say what they think their doctors want to hear. It can be reassuring to the patients when the physician tells them: "I know it must be difficult to take all your medication regularly. How often did you miss taking your medicines?" Osterberg and Blaschke (2005:490) found this approach most efficient for making patients feel comfortable in telling the truth and for facilitating the identification of poor adherence.

There are acknowledged associations between treatment adherence and a variety of support systems. Gottlieb (1981:12) defines a *support system* as perceived availability of help or assistance from other persons during times of felt need. A few definitions are in order to put this in the proper context. *Social structures* are sets of norms and values that define the range of behaviours and kinds of interactions permissible within a culture for specified classes of individuals. *Social organisations*, like welfare and hospices, are the observable manifestation of these norms. *Social networks* are concrete relationships among a defined set of individuals. *A social support system* is a subset of an individual's ego-centred social network upon which that individual relies for social support (Gottlieb, 1981:12). Supportive social structures have long been recognised, at least at an intuitive level, as playing many important roles in the lives of people. Anthropologists have pointed to the primary group as the major environmental influence on the behaviour and attitudes of the individual (Gottlieb, 1981:97). Recent surveys (Orrell, 2005:171-176; Orrell *et al.,* 2003:1369-1375; 2001:483-484; Osterberg & Blaschke, 2005:487-488, *cf.* Janzen notion of therapy managing group pp 92-93) suggest that social networks play a significant role in the adjustment process after testing positive to HIV. The size of an individual's social network – i.e. the number of supporters the patient has available to call on - enhances adjustment to social problems. People usually look to others, particularly members of their families, for validation and assessment of their personal characteristics, and for feedback about their behaviour. This is particularly true when a person is stigmatised. A good deal of evidence suggests that self-disclosure to a few close acquaintances is an important component of healthy personality adjustment. On the other hand, poor family support and abnormal family functioning have been suggested as risk factors for non-adherence (Sibbald, White & Pharoah, 1988:14). A distinction needs to be drawn between general social support and that directly related to the disease, the latter being the more important. A distinction is made between primary and secondary support: while primary support is rendered by the family; secondary support is rendered by friends, neighbours, the church and welfare organisations.

Context is another complicating factor in the doctor-patient relationship. Helman (1990:142) distinguishes two aspects to this context, both of which play a meaningful role in treatment adherence:

1) An *internal context***,** comprising prior experiences, expectations, cultural assumptions, explanatory models and prejudices (based on the social, the gender, and belief systems) that each party brings to the clinical encounter

2) An *external context*, comprising the wider social influence, which defines the patient's actual living setting. This includes social support (family, friends, neighbours and the broader community) and social and economic factors (poverty, discrimination, stigmatisation, gender roles and employment/unemployment).

It is particularly relevant to understand the role of both the internal and the external contexts that may have contributed to the origin, presentation and prognosis of ill health. A consideration of context also helps in deciding who the real patient is, and whether the focus of treatment should be on the sick individual, or his/her family, or the community in which they live (*cf.* Helman, 2000; Kleinman, 1980).

Adherence to prescribed medication is a complex phenomenon that depends on the interaction of inter alia medicinal, personal or economic factors. Good nutrition, personal and environmental hygiene, and a healthy lifestyle all contribute to ARV treatment adherence (Osterberg & Blaschke, 2005:491). All the previously mentioned indicators are possible when access to resources, especially money, is easy. Household size is an important proxy of socio-economic status, with larger households generally facing more severe resource constraints because available resources have to be divided amongst more people. The assumption is that patients from smaller households are more likely to adhere to treatment than are patients from larger families. Patients with better access to public services, access to a flush or chemical toilet and access to piped water are likely to display higher levels of adherence than those without. Thus, the above suggests that patients from poorer backgrounds are relatively less likely to adhere to ART than are patients from better-off backgrounds.

Care and support

In this study it was found that the quality of the care and support given to people with HIV/AIDS depended on household type. Households in the Bolokanang communities fell into three categories: single-person households, nuclear-family households, and extended-family households. People who lived alone were often left to care for themselves, a situation less likely to occur in nuclear- or extended-family households where day-to-day support may be more forthcoming because of bonds of reciprocity. Provided they could manage the stigma associated with HIV and AIDS, households in Bolokanang generally responded positively by providing care and support to an infected household member(s). Apart from sympathy and care, families also provided emotional and financial support (which contributed positively to adherence). However, the nature of care provided varied among household backgrounds. Poor people generally came from wage-labour households who earned in the mornings and ate in the evenings, or they subsisted on day-to-day wage employment. If they could, they worked in the non-formal sector, e.g. doing construction work that is not covered by labour laws or social security regulations. People from such backgrounds constitute the majority of people living with HIV and AIDS. They have neither job security nor guaranteed access to social welfare benefits. As a result, they often have to choose between recovery and going hungry. In this study, most people with HIV and AIDS from such impoverished families continued to work intermittently and therefore had less time to care for themselves. For poor families, someone with HIV and AIDS at home meant a loss of income, since many of those infected were breadwinners. As a result, poor people with HIV and AIDS did not usually seek care until the final stages of the disease.

The role of family

Although changing in size, structure and function, the African family has persistently maintained its place as the central human social unit in the African context. Beyond the traditional African household, whether in the nuclear or extended form, is a network of people, most of whom are connected by kin or blood relationships. Patterns of family treatment and care are deeply embedded in this wider kinship system (Ankrah, 1993:7-9). On a functional level, we see an illness in which people other than kin often play vital care-giving roles. In all family types, family care giving for people with HIV and AIDS brings about role reconfiguration and financial and other impacts. Households affected by the pandemic access various forms of support mechanisms to mitigate this impact. These forms of support are outlined in the following section (Ankrah, 1993:7-9).

Communities (including friends, neighbours, church organisations, and governmental and non-governmental organisations) have in most situations risen to the challenges of providing care to households struck by HIV and AIDS.

The role of the community

Community-based care and support programmes are viable options to complement primary care in assisting households to cope with HIV and AIDS. However, the social contexts in which such programmes operate are often not conducive to community-based care because of high levels of stigmatisation, fear of HIV, intra-household conflicts and local beliefs about the aetiology of HIV and AIDS (Arntz, 2002:18). In a recently published database of HIV and AIDS service providers, the AIDS Training, Information and Counselling Centre (ATICC), the National Association of People Living with AIDS (NAPWA) and Hospice - all non-governmental organisations - play instrumental roles in communities ravaged by HIV and AIDS.

Apart from formal organisations' significant responses to people living with or affected by HIV and AIDS, the challenge to communities has been to form a rich diversity of self-help organisations. These community-based groups provide a wide range of information, counselling, care and other support services, and, as such, form the backbone of the fight against HIV and AIDS in many communities where government services are either limited or inadequate to address HIV and AIDS (Arntz, 2002:20). These self-help organisations are set to function only if stigma is removed. Archbishop Desmond Tutu (*City Press*, 14 February 2004) echoed this sentiment:

> Silence kills, stigma kills. We do not want those living with HIV to be the modern equivalent of the biblical leper who had to carry a bell and a sign saying, 'I am unclean'. They are not unclean. We should embrace them physically and emotionally as members of our community.

Community support at the local level is the key both to ensuring an adequate and timeous response to HIV and to combating stigma and discrimination. According to Mugyenyi (2005), community efforts to tackle HIV openly and reduce the negativity attached to infected people have borne fruit in countries such as Uganda. In his paper he reiterated that community - although part of the support network - served a different function and a lesser role than did immediate family members.

Among health care professionals, the predominant approach has been to focus on attempts to identify patients most at risk of exhibiting non-adherent behaviour (Rosner, 2005:553). Wamala *et al*. (2007:4) report the role of socio-economic status in explaining differences in adherence: lower income or a poorer socio-economic environment is associated with lower levels of adherence. In all societies disparities between the rich and the poor are not only evident in the lifestyle of the two groups; it also manifests in divergent illness profiles, with the poor being disproportionately affected. In most developing countries, rural communities specifically, the link between poverty and poor health remains very strong. Quite often those living in poverty are trapped in a vicious cycle: they are undernourished and ill. Other factors deemed important to consider are reflected in Table 5. Some of these factors may defy immediate solution, but many of the most common causes of non-adherence are indeed modifiable.

Table 5 lists major predictors associated with poor adherence. When these predictors are present, physicians should have a heightened awareness of the possibility of poor adherence. Osterberg and Blaschke (2005:490) maintain that even patients in whom these indicators are absent do nevertheless miss taking medication as prescribed. According to Chesney (2000:S171), the critical factors that influence adherence, fall into four main groups: (1) patient factors, such as drug use, alcohol use, age, sex, or ethnicity; (2) medication regimen, such as dosing complexity, number of pills, or food requirements; (3) the relationship between patient and the health care provider; and (4) the system of care.

Table 5: Key risk factors regarding non-adherence

A. Patient and treatment factors

- Patients' cultural and ethnic backgrounds
- Lack of knowledge about treatment regimen
  - Regimen complexity
  - Beliefs and attitudes concerning the effectiveness of the treatment regimen
  - Low levels of health literacy
  - Poor understanding of the purpose of medication and impact on health outcomes
- Living alone or not having a caregiver
- Lack of motivation and/or inconvenience
- Impact on the patient's lifestyle and need for changes
- Comfort or discomfort associated with treatment regimen
- Discordance between physician and patient

B. Lifestyle factors

- Environmental limitations, such as poor housing
- Resource limitations, such as no transportation to the clinic
- Lack of awareness of illness and of the consequences of non-adherence

C. Socio-demographic factors

- Age, gender, level of education, smoking, drinking, illegal drug use
- Marital and socioeconomic status

D. Psycho-social factors

- Denial of illness
- Patients' perceptions, beliefs and attitudes
- Previous poor experiences with treatment regimen
- Lack of social support system

Gethin (2002); Rosner (2005); Zerwic, Simmons, Wung (2003)

Although it has been well demonstrated that certain patient demographic characteristics increase the risk of HIV infection, other demographic characteristics of patients have not consistently been found to be predictive of poor adherence (*cf.* De Reuck 2008; Stone 2001). Studies on adherence correlates indicate links between various patient psycho-social factors and non-adherence to ARV regimens (*cf*. Aversa & Kimberlin, 1996; Horne, 1999; Mehta *et al.,* 1997; Rosner, 2005).

3.7 CONCLUSION

This chapter has attempted to broaden the patient-focused approach to the understanding of aetiological views and treatment management by incorporating other factors of the patient's socio-cultural context. Despite there being evidence to support the need for culturally meaningful and informed treatment programmes, there is however surprisingly little research that examines specifically patients' beliefs about HIV, AIDS and ARV treatment from a socio-cultural perspective, research where patients have direct experience of and are directly affected by this deadly disease. Particularly in resource-constrained settings, public health education on HIV and AIDS and adherence behaviour needs to be based on a better understanding of the socio-cultural dimensions of the patients. Although people can or may hear these messages, and do indeed understand them, they nevertheless fail truly to comprehend these messages and then to incorporate them meaningfully into their lives and behaviours.

The aetiological views discussed above have both strengths and weaknesses. The strength of Foster's views is the recognition that, in many societies, illness is not viewed as a discrete and relatively independent domain, but is rather considered under a widely applicable explanatory framework for the explanation of ill health. What I found to be lacking in Foster's views, is that there is no reason why personalistic and naturalistic explanations should be mutually exclusive. Where multiple explanatory frameworks are present in societies, Foster does neither address the implications nor how this multiplicity affects classification, especially because biomedicine is today, in many societies, widely accepted (*cf*. Erstad 2006). I should like to imagine that many people will see these rather as complementary systems and not as systems in competition. Several general views exist – e.g. natural/unnatural and pollution beliefs - for categorising theories of illness causation across cultures. These views facilitate the understanding of how ill health is perceived and dealt with by patients in diverse cultural settings. Although these views have been around for some time, their continued relevance has been attested to by recent medical anthropological research - research that organises discussion of cross-cultural variability in aetiological understanding with reference to one or both of these views (*cf*. Garro, 2000:305-332; Thomas, 2008:227-255).

While it is best to be wary of invalid generalisations, it would appear that among certain ethnic minorities and non-western cultures, families, not individuals, are regarded as the locus of responsibility for taking decisions on health care. A patient's illness and its treatment system is a complex process that requires an intervention that acknowledges and understands these complexities so as ultimately to improve treatment adherence.

Adherence to ARV treatment has emerged as a critical predictor of HIV treatment success. Continuing the process of introducing ARV medications, and optimising the treatment outcomes of individuals living with HIV and AIDS in South Africa require careful attention to factors in the patient's socio-cultural context. It is clear that ARV treatment needs to be part of an integrated/holistic treatment package that includes prevention, care and support activities, all of which complement and reinforce one another to enhance medication adherence. A sound understanding both of the predictors of poor adherence and of the demographic groups most at risk, has important implications for clinical practice, health system management and service delivery. Traditional herbal remedies against HIV and AIDS are often taken alongside biomedically prescribed drugs (ART), thus possibly influencing the efficacy of the latter. Awareness of the logic and the modalities underlying alternative perceptions of HIV, AIDS and ARV treatment on the part of health planners and health practitioners may facilitate communication with, and secure adherence by patients in pluralistic medical settings.

CHAPTER 4: UNHEARD VOICES: EXPERIENCES OF PATIENTS ON ART AT PETRUSBURG

4.1 INTRODUCTION

People living with HIV and AIDS, specifically those who are on ARV treatment, must strictly adhere to both antiretroviral regimes and to scheduled clinical appointments for both optimal treatment outcomes and prolonged quality of life. Adherence is therefore an imperative, because non-adherence seriously undermines the benefits of ART, increases drug resistance and moreover increases HIV-related deaths. Many factors have been reported to be significantly associated with patient adherence and non-adherence to ART and clinical appointments. Little is, however, known about the obstacles that patients face in adhering to the regimens or about what - if anything - helps patients to adhere in resource-limited communities like the one at Petrusburg. Identification and understanding of context-relevant factors are important for the development of effective adherence interventions within the ART programme and for informing policy and treatment guidelines.

This chapter analyses (*cf*. 1.3) the empirical data collected. The data collected are analysed with a view to gaining understanding of the factors that influenced adherence to ART in the Petrusburg community. The process involved reading through the field notes - which included the semi-structured interviews with informants and the focus-group discussions with ARV users – in order to identify key themes. A general thematic analysis focusing on similarities and differences of perspective between informants was next conducted. Further analysis revealed that the themes appeared to be linked. These were then analysed together. Information was analysed to capture the different perspectives of the informants. Where views coincided or where they differed, these were shown. The data were analysed to report on the role played by patients' socio-cultural context in respect of adherence or non-adherence outcomes regarding both ART and clinical appointments. Through the analytical process that helped me to detect recurring themes within the accounts informants gave about their life experiences, I discovered how they understood and made sense of their lives while on ARV treatment. I am under no illusion nor do I argue that the ethnography presented in the following pages is representative of all cases, or that there is necessarily truth behind everything I was told. I am attempting merely to represent, as truthfully as possible, the people, the stories they told me, and how they experience their lives. Yet the risk of misrepresentation always exists. To produce general anthropological knowledge from individual experiences in the field is a tricky business (Hastrup & Hervik, 1994:1). To produce general anthropological knowledge from individual experiences of suffering is even trickier.

From the informants' narratives, themes were derived from patterns such as conversation topics, which included experiences, recurring daily activities, meanings and feelings. Important and frequently mentioned ideas were grouped into coding categories, for example, barriers related to informants' social/physical environments and facilitators related to the informants' use of social support.

The presentation of narratives will be followed by the discussion of the research results.

4.2 POST HIV-POSITIVE TEST DIAGNOSIS

Similar to other chronic diseases, the course of HIV infection varies with the individual, changes over time, and can be shaped and managed. What now follows is a tale told by an informant while reliving moments of shock after diagnosis.

It's a lonely journey but I chose to live:

> After the initial shock I went into complete denial. You see I chose to ignore the fact of my status even though at the back of my mind I knew over the years on several intervals I will re-test just to make sure, and the result was still the same. I chose to just continue with my life and pretend like nothing has changed. I did some readings on the virus, and the books I read was not inspiring as it spoke about the toxicity of the treatment, the stages of the virus and so on, which, frankly, was not something that I wanted to hear at that time. Needless to say, I did

not bother doing any viral-load and CD4-count tests; after all, for all intents and purposes, I was healthy. Years went by and I read and heard of people dying of the disease, listened to people's perceptions about the disease, saw people getting ill from the disease and still chose to be in denial about my status. Of course, from time to time in my alone moments, I will think about the virus living within me so I did what I thought was best: surrounded myself with people all the time, went out partying, had lots of friends (in reflection I realise that it was my way of trying to escape what was happening to me). Even when I had an odd cough or a feeling of being unwell, I will not share with anybody for fear of what I will hear them say ("You have bio-slim" - that's what they call AIDS locally), never mind my circle of friends or family. In order to keep it to myself, I would drink self-made home remedies and they would help, but going to the clinic so often was just going to trigger suspicion and eventually get them talking. This continued for years when I had what seemed to be a cold, and the nurse told me its pneumonia and she suggested that I see the doctor. I asked her for some treatment while waiting for the doctor. The treatment did not work of course, and I continued to have this cough. The doctor then suggested we do an HIV test, I did not tell him that I had tests done years ago of which all came back positive. I think I was still hoping for my miracle. HIV is a lonely life, no matter what anyone tells you. The looks on doctors and nurses when they share the news with you; friends and family who don't understand why an old man my age and married gets infected; potential dating partners who run for their lives when they hear you are infected; all the pills; not knowing how much longer I will be able to maintain good health, and the dread of having to go to the clinic like a pregnant woman, I don't think I can handle that....

The tests came back positive, not that I was surprised and he also did a CD4-count test which was at that time very low. This is when I started to pray like I never prayed before. When I began to get my sense back, there was one thing that was clear in my mind and that is I NEEDED TO TELL PEOPLE CLOSE TO ME ABOUT MY STATUS. Once I had done this, the next step was to take a decision to LIVE - so this time around I spoke to the doctors and nurses, I read a lot of stories on people living with the virus, treatment options, I did a lot of my own research because, finally I realised that ignoring the disease won't make it go away.

Was it as easy as I say now? A big NO.

First stigma, we are treated like people with leprosy; you remember the story from the Bible? Nobody wants to be close to us, to be seen walking with an HIV-infected person. It just scares me listening to my friends discussing how they would react if one of us might be infected. I mean those conversation gives you an idea of what to expect, and because you appreciate their friendship and don't want to lose them, you decide to keep it a secret. I told my employer and, because I was more at home than at work, I eventually lost my job.

What happens now?

> Okay, you know your status, and you start to realise that you are not dead and you are not going to die in the next weeks. So you get yourself back into shape. So, basically, you start to see the world with new challenges, but this life is not easy - I mean being HIV infected – it's no game in the park. I have given my life to God, because I should have been dead long time ago, but I am still here and not because of my will. I know that my God has a reason for keeping me going. Giving my life to God has helped me make peace with what has happened, I even forgave whoever passed the virus to me. I am just still angry with myself, because I did nothing to prevent getting infected. What I am still doing is still learning to love myself; learning to love the part that I want to hide from people I care the most about, that is my children, wife and my mother. How I survived, is only by the miracle of God, because death was knocking. I thank God for the strength he has given me to fight my enemy (HIV).

From the above it is clear that diagnosis with HIV affects almost every aspect of a person's life, including relationships, employment and the tasks related to daily life (*cf*. Kalichman *et al*., 1996). Studies investigating HIV-infected populations have frequently shown an increased vulnerability to symptoms such as despair and guilt (*cf*. Thompson *et al*., 1994). Associations between high levels of depression and having an AIDS diagnosis have consistently been reported (*cf.* Judd *et al.,* 1997). While most studies have examined relations between HIV and psychopathology, some studies have found HIV and AIDS to be associated with other domains of psycho-social impairment. For example, HIV-sero-positive people have been found to experience more sexual difficulties (*cf.* Catalan *et al.,* 1992), and show poorer levels of adjustment within vocational, domestic, sexual and social domains, than do sero-negative people (*cf.* Pakenham *et al.,* 1995).

4.3 ARV TREATMENT

Based on what is known about HIV resistance, once PLWHIV begin ARV treatment, it is imperative that they adhere to the regimen. Patient adherence is vital to the successful development of effective antiretroviral combinations. However, the prescribed regimens are extremely complex and frequently require some lifestyle changes (*cf*. Erlen & Mellors, 1999). For example, PLWHIV may need to coordinate dosing schedules, timing of and/or content of their meals, and self-administration of their medications with their daily schedule. The complexity and burden of planning for and implementing the self-administration of medication challenges the individual and increases the person's risk of non-adherence. Although studies continue to demonstrate the benefits of ARV treatment, little is known about the patient's experience of living with this regimen.

This is how I got to ARV treatment:

> Six months later (post HIV+ diagnosis) I had to go back to the doctor for my bi-annual check-up and CD4- and viral-load test - the results came back and my viral load was <50 and my CD4 count was 120. The doctor advised me to immediately go on ARV treatment and I agreed. After prescribing the ARVs, we spoke of the possibility of side effects and the importance of taking the tablets as prescribed. The next milestone was to go to the dispenser to get the pills and feel the discomfort of having to see the pharmacists giving me the discreet look and wondering what the heck they were thinking. Having survived that episode, the next [step] was to get home, open up my package, and read about possible side effects of the various tablets I was given. To say that I was scared out of my mind will be putting it lightly. Then came nightfall when I had to take my tablets. Within an hour of taking the tablets I started hallucinating - then I got really scared. I jumped out of my bed went into the bathroom looked at myself through the mirror and the sight of what I saw nearly drove me insane - my face looked puffy, my eyes looked like I had seen a ghost, the right side of my face was shaking and I thought I was going to have a stroke. I struggled in the first two weeks, whilst my body adjusted to the treatment and I had a few side effects, but within no time my body had gotten used to the medication.

ARV users take at least a three-drug combination and they have to take these ARVs at different times, sometimes alongside other medicines for the treatment of opportunistic infections. Whilst acknowledging the strides made to address dosage challenges (fixed-dose combination[48]), I realise that ARTs are still

---

[48] Fixed-dose antiretroviral combinations are products that combine two or more active drugs in one tablet or capsule. The introduction of fixed-dose combinations (FDCs) brought about many potential advantages. Most obvious are the simplification of what is supplied to and taken by individual patients, and a reduced potential for the inappropriate sharing of drugs. Simple regimens and regimens that fit into a patient's lifestyle enhance adherence. Patients talk of incorporating the regimen into their lives and of it becoming a way of life. As a

reported as complex and inconvenient treatment to take under a very stringent time schedule. Some informants complained about the demanding drug regimens and about the size of the individual pills they had to take (especially those on Efavirenz). These challenges were related to the sheer complexity of the regimens, including taking medications at assigned times, with or without food, with enough water, and with or without other medications. Sometimes, the magnitude of this complexity was simply too much for them, and they were unable to do what had been required. This often becomes a problem over time, especially when too many different medicines have to be taken at once. These characteristics increase the likelihood of poor adherence to ARVs, especially among people living with HIV and AIDS who are less educated and moreover try to conceal their health condition.

Being on ARVs is an everyday challenge

> We might be getting the pills for free, but the conditions and management of ARVs are not an easy task. Challenges we face everyday are in the form of support (maybe partly our problem, because we are scared to disclose our sero-status), remembering to take pills, food (nutrition), and adherence. If you miss a dose, it's a problem, for both the clinic and myself; if you drink your pills later or earlier than the set time it's a problem for both the clinic and myself. Yes, some pills we can take on an empty stomach and others we cannot. I must tell you that my stomach is mostly empty. I don't know if it's only with me, but since I started taking ARV treatment my appetite went up. I eat like a pregnant woman. It's a good thing for people with food, and sad news for us that are not even sure where my supper is going to come from. Let me tell you, there has been days in my life I had nothing - and I mean *nothing* - to eat and obviously I would not drink the medication due to side effects (*cf.* socio-economic challenges). My strategy: I will visit say a friend or family around 5:30 p.m., so that when they start cooking they cook enough so that I can get a share. I will sit and will not leave until they dish for the family and hope that they will offer some for me. There are two things that I want you to take note of from this scenario: one, eating is not a guarantee or a given for most of us; and secondly, taking pills depends on the time I get home, all which impact on my routine and ultimately [on my] adherence.

---

regimen increases in complexity, its inconvenience makes it difficult to incorporate into daily living.

> Support (both emotionally and financially) is another big challenge for us. The best support I am enjoying currently is from this group, because we all share the same problem and [are] probably facing [the] same challenges, although the level varies. I am sure others, especially those with disclosed status, will not share this sentiment. Nonetheless, support is important if one is to survive this challenge. Financial support is probably wishful, but an important necessity or addition if we are to live longer. Who has the money to give me every time I need to buy supplements or food? Do you have? Food is expensive, [the] nutritious food the doctors, nurses and media keep talking about it is even worse. In comparison with other HIV-infected people, I think I am in a better position, because I receive a government grant, but it's also not guaranteed. Once I look better, the doctor will simply not recommend to the Department of Social Welfare to renew my grant for the next phase, and then what? No wonder people default so that they can remain in the list of grant. Sorry, but it is the only income and once that is taken away, then life will be a mess. If we are to live healthy, our living conditions would have to go through drastic change. We hardly drink fresh water (clean running water here is a nice to have not a right like the constitution say); we use toilet facilities that nobody would opt for if they could choose. One of the reasons why so many people did not want to be part of this study was because they were ashamed of their living surroundings, especially when you said you will come to visit us.

> ARV pills are my life-time partner and I appreciate them. I am sure many people will kill to be in my position. However, having to down so many pills every day has its own share of irritation and disgust. They are many, big, smell[s] and taste bad. I practically have to psych myself up every time before I can drink them. No wonder people go on pill holiday, something I heard from nurses.

Furthermore, informants reported facing many challenges to taking their medications as prescribed. This statement is supported by the following comments:

> Although the medication brought more hope to a better prolonged quality of life, every time I take my medication, I am directly and/or indirectly reminded that I have HIV.

> At times I take more than the recommended dosage, and the doctors always advise us not to. I do this, because I hope to get better fast or maybe by chance heal.

The social environment in which patients in the study took their antiretroviral medication was another important factor in patients' adherence to regimens. For some informants, being in a public and/or unfamiliar environment was an obstacle to taking their ARV medications. For some informants, such environments were not considered ‘safe’ places to take pills. Specifically, male informants stated that “*they did not carry their medication with them, because despite not wanting to be seen taking pills, they could not carry handbags with them*”.

Other informants indicated *“an uncomfortable feeling especially if we have to take medication in front of others who do not know about our HIV status*”*.* In general, informants discussed the embarrassment and stigma associated with taking ARV treatment in public.

> People ask and sometimes one runs out of lies. Besides, I don’t want to be seen while taking my pills. Really that does not make ARV life possible, because you have to think of a lie to get to your pills. I call my medication *Disemmy Tsaka (name given to ARV treatment)* just to lose sight. Adherence has been a challenge. I remember I went to spend the night at my mum’s and I forgot my medication, there I missed a dose, possibly two. That is always an issue, especially taking pills in front of strangers or people who are not aware of your status. Times like these, especially if your life it is on line, you start realising the importance of your family and you will do just about anything to mend possible conflict and restore peace. When everybody is turning their backs on you, your family will always be the answer. I am grateful for their love and support, otherwise I would not have made it this far.

> It is really inconvenient and somewhat embarrassing, like I remember times where I was at [a] friend’s house and here I come popping *dikoma* (pills holder/container), laughter and somebody asked: ‘since when are you on snuff?’ I’m like, ‘it’s my medication’. And I was like [after a long silence] thinking of something to tell them, because I was not going to tell them what it is for. Then I said, ‘none of your business’.

> Although a challenge on its own, I am taking ARTs trying to keep my head-up for me and my children, although other people keep bringing me down. Sometimes I will go for a month just taking my medication as a daily routine and not even thinking about what they are. And then, other times, I will look at them and be reminded: I have this dreadful disease. Now I am at a point where I will look at them and think, ‘Wow, these are what’s keeping me alive’.

Telling people what medication they are taking and going to a clinic or hospital (either for refill or clinical appointment) is a communal concern that makes it difficult to conceal infection from the neighbours. It is seen as an implicit way of disclosing one's HIV status. Some informants believed that people would be able to deduce their status simply by either seeing them consume their medications, or by their regular visits to the local clinics. The barriers indicated above show that HIV and AIDS patients on ARV treatment faced many challenges in taking their antiretroviral medications as prescribed and also in adhering to clinical appointments. Studies on adherence have shown that even minor deviation from the prescribed medication regimen, such as missing a dose, could result in subsequent treatment non-adherence (*cf*. Orrell, 2005; Orrell *et al*., 2001).

In many resource-limited communities, the roll-out of ARVs has been a remarkable expression of international solidarity. However, Farmer *et al.* (2001:404) contend that starting patients on ARVs without also ensuring full adherence through an adequate support system is likely to lead to treatment failure and the emergence of drug-resistant viruses that can be transmitted to others. Drug-resistance is a potentially major threat to achieving universal access in that it could mean that more and more people have to switch to second-line ARVs, which are both more expensive and more difficult to use. The major increase in programme costs brought about by this would result in fewer people gaining access to treatment.

ARV medicines tend to increase the users' appetites. Informants reported being unable to match food supply with increased appetite as they began to feel better. Lack of food was seen to frustrate patients' determination to take and adhere to ART, since they had nothing to eat as their appetite improved. Notwithstanding their having increased appetites, dietary restrictions further add to the complexity of ART and often require adjustments in lifestyle. Patients can find their meal schedule compromised by ARVs that need to be taken on an empty stomach. This can be particularly difficult if family or friends are unaware of a patient's HIV status (*cf.* Aversa & Kimberlin, 1996). To assist PLWHIV to adjust to their prescribed regimen, health care providers need to understand the ways in which the daily lives of PLWHIV are changed or remain the same because of taking ARVs (*cf.* Erlen & Mellors, 1999).

4.4 PERCEIVED CHALLENGES OF ADHERENCE

Informants in the study expressed many competing life issues that act as barriers to their medication adherence (*cf*. 4.2 and 4.3). Themes that emerged/emanated from analysis of narratives include: negative experience of social stigma; patients' social and physical environments, specifically poverty concerns; lack of social support and financial difficulties; inadequate knowledge about ART; poor doctor-patient relationships; and, conflicting cultural views.

4.4.1 Patients' socio-cultural contexts

Relatively few ARV-treatment studies have addressed adherence beyond the clinical level and have neglected, among other things, to consider patients' socio-cultural contexts. An understanding of the socio-cultural context factors associated with adherence and non-adherence is necessary to inform interventions to improve self-care and health outcomes in the population of patients on ARV medication. The medication-taking and the socio-cultural contexts of the informants were investigated, and the results of this study provide support for the importance of including the socio-cultural context in the roll-out of antiretroviral treatment.

Discussions in the following section firstly describe the implications of HIV on the family structure. This is deemed important, because, next to the infected person, the people who are most directly affected by HIV are the family of the infected person. Secondly, the discussion looks at factors of the informants' socio-cultural contexts that pose a challenge to treatment adherence. This is followed by a discussion of factors within the socio-cultural context that enhance treatment adherence.

4.4.1.1 Family social structure

My son, mother, sister, boyfriend and my HIV status

"I was diagnosed in 1998 - I can't even remember, but I think around then. I had a thought that I might be sick when I could not get around the things I was use[d] to doing everyday at my work (like cleaning the house, doing laundry, and the usual domestic work), but I did not let that thought stay in my head for long. I am a single mother of one child who just wanted not to be alone, wanted someone to help me in this walk through this thing called *life*. Anyway, my son became scared when he saw me sick in bed for more than ten days not getting any better. He got my family (especially my mother) to come and stay with us during those days. Later [I] could not walk with legs that keep swelling. So they got me to the doctor who told me I had TB. So I was admitted, and after some time showed no signs of recovery and they (doctors) asked would I take an HIV test. I agreed, and my mother asked if they could take me home for a weekend to take care of me while waiting for the test results. My first stop home was by the local traditional doctor (prophet), [a] well-known lady. She massaged my legs and the swelling got better, she gave me some herbs to cook and drink and oil to rub my legs with. So it went on for a month and there was a slight improvement, but the scary feeling on that dying bed motivated me to try whatever human[ly] possible. I did not care; I just did not want my son to have that look in his eyes anymore. My poor mother was on a mission to get me back on my feet and she went out to look for medication, the likes of *Aloe extra*, *123 You Are Up.* I can't even remember all that I had to drink. Remember, I was not working, and for the kind of job I was doing, no work no pay, so she used her pension/old-age grant money. I was eventually up and went back to work, but the lady I was working for was not keen to take me back. She started asking questions around my health, what was the problem, and so. She finally got me something to do on condition that I never miss so much [as a] day of work. I think I worked for two months or so, and then I was back on that dying bed. I went back to the hospital and I could not avoid the results of the tests. During my second hospital stay, a young female doctor came into my room and asked if I would prefer to have anyone with me when she discussed my results for the HIV tests. Then I knew they will be positive. Now, there was no way that I will expose either my son or mother to that, so I decided I will invite my sister to be with me. You won't believe this, but then we (my sister and I) were not on speaking terms, because I thought she was in a bad relationship and she would not quit it. I mean I could not understand how she could love a man that blackens her eye. See, because the men in my past had not blackened my eye, they just never stayed around. Anyway, I eventually got my sister to the hospital and, yes, the test was positive, I mean that is why we sitting here. I cried on her like she was my mother and all I could think of was I have been handed a death sentence. I just recently met someone, who I really cared for, so when I learned about my HIV status I did not

> know how I was going to handle this without losing him. I was not worried about him getting it from me because we had protected sex, I mean the relationship was still knew, so I could count the many times we had sex. Every time he came to see me, I would spin a story for him and for my son and mother."

The work of Peuegnant *et al.* (2001:3) has demonstrated that when one member of a family has HIV and AIDS, the whole family feels the impact. The impact usually shows in many different aspects. First, the economic hardship associated with HIV and AIDS - primarily emanating from loss of income - can be devastating. Although not well documented, employers, especially domestic, often fire employees, because they have tested HIV positive, from fear of transmission. The combination of PLWHA's increased health care requirements and decreasing family income caused by PLWHA's unemployment may even hinder access to basic goods, such as food and housing. In addition to economic hardship, families living with HIV usually face tremendous social pressure and discrimination (*cf*. social stigma). Bor *et al*. (1993:188) point to a strong and supportive family as one of the first lines of defence in the face of societal discrimination and other hardships related to HIV and AIDS. These authors (1993:189) further suggest that when immediate parents or siblings are themselves too busy to take care of the infected person, the grandparents usually become the primary caregivers in respect of their grandchildren (*cf*. Lili *et al.,* 2006; Peuegnant *et al*., 2001). Burgoyne (2005:114) has found that PLWHA who are on ART, experience better clinical benefit if they perceive social and family support to be available.

The above underscores the need for further context-specific research on the household and community response to ill health and on the implications to the family social structure. Such work would, in all probability, demonstrate more comprehensively the huge burden of illness for households in resource-limited communities and add weight to national and international calls for more investment in disease prevention and pro-poor curative health services. National and international research efforts also need to develop a common illness cost-and-impact methodology to allow more meaningful comparisons of the economic burden of illness across settings and diseases. Furthermore, the study recommends an enforcement of appropriate legislation to protect the rights of people in employment to access treatment without fear of discrimination or loss of jobs.

Changes in family functioning resulting from HIV infection occurred mainly in the role functioning and the responsibilities of healthy family members, in the sexual relationships among couples, and in care and support. The informants had differing occupational statuses, such as having been employed or unemployed prior to learning about their HIV infection. Those who had at the time been employed had irregular attendance at work due to frequent illness episodes, which later led to termination of their working contracts. The informants also reported the changing role - from that of breadwinner to ill person. This resulted in role changing within the family, whereby other family members had to play multiple roles, thus being burdened with extra responsibilities, such as patient care in the family, apart from having to do the regular household chores and having to work overtime in order to earn additional money.

Changes in role functioning and the fact of healthy members taking on additional responsibilities have been documented. While Bharat (1995:78), on the one hand, indicates that caregivers of PLWHAs have to play multiple roles, and that this causes strain and burden, Akrah (1993:7), on the other, observes that caregivers have to quit jobs in order to stay home to look after the infected individuals, which results in additional burdens on those persons who are primary caregivers. Informants in the present study reported that increased responsibilities caused definite stress on the family members with regard to their role performance. Informants perceived themselves as being unnecessarily burdensome to other family members. Furthermore, caregivers had to limit their activities outside the family since they were required at home ‘to look after us’ (infected persons). Interestingly, this was not reported by informants as placing a burden on them. The family accepted this change as it was expected of them to look after the ill family members (*cf*. social capital).

4.4.1.2 Social stigma

In this study, stigma emerged as a barrier to both ARV treatment and scheduled clinical appointment adherence. Although some people are accepting and supportive, others overtly reject or subtly distance themselves from the person with HIV.

I am treated like dirt for being HIV positive

> Getting tested for HIV is a big step. But when the results come back positive, one has an even bigger question on his or her mind. The decision whether to disclose or not is a difficult one for people diagnosed with what I call a killer virus. I am not surprised why people keep quiet about it; it really [is] a tall order. Those that disclose to the people closest to them get all the love, care and support they need at times. But in this day and age when everyone knows all the facts about the virus and how it can be spread, it is unfortunate to encounter people living with HIV and AIDS being rejected, or at times ill treated by their family members and members of the community. I remember after receiving counselling and getting the results I decided to tell my wife, but I did not have the courage to tell my children. I was hoping we will work something out with my wife and later tell the children. Unfortunately, I did not get the reaction I expected. I initially thought my wife will comfort me and give me support, instead it was blaming, and she practically turned against me and treated me like an outcast. I just did not know how best to handle the situation, especially with children around us. She made me feel dirty, called me a cheat, like I have probably infected her. She told me to stop touching her children, that it's enough that I brought so much shame to the family. My infection brought tears, sorrows, agony and curse to my family, and that made it really difficult for me to accept the results and start working on the life after infection. I lived a lonely and sad life and did not know how to win my wife's trust. Ooh, this is horribly painful, reliving moments - I am not even sure I can do this. Anyway, please excuse my tears; I will do this like a man. I hope you will learn something out of this and not fall in the same trap. I gathered courage and was doing fine for myself....but then I told my parents before anybody beat me to it. Wasn't that another biggest mistake? My own parents, siblings turned against me much more than my wife. It really broke my heart. I was practically reminded everyday that I have HIV, and they will tell me to die faster to end the shame I brought to everybody I related to, either kin or [by] marriage. Each day I just sat alone crying, imagine a Xhosa man, that's a woman thing [laughter]. I thought people, especially my own family, both nuclear and extended would be open-minded about the virus and be decent enough to give support or just keep quiet if they have nothing positive to say. Did I develop some hate? Were there any family ties left after

> these experiences? I am not sure, but, hey, you can choose friends but not family or what? I had to think like a man and find means to get some cure. I have tried everything possible and I might say it helped, until my body could not cope with the virus. I decided to visit Bophelong, our local clinic, and was told my CD4 count its low and was expected to start the medication screening [drug-readiness training]. It took long, but I had to stick it out for better health. Part of the process was my introduction to support group or treatment buddies. You won't believe what I am going to tell: they are family, they give me support and it feels good to be around them.

> With one of my visits, the nurses told me the biggest threat to my health is stressing. They said I should stop stressing, but that is impossible to reverse because each day I am reminded that I am HIV-positive, if it's not by the pills I am taking, then one of my family members. I don't need to be ridiculed because of my status. I am HIV positive and I don't expect pity from anybody. All I want is for people to be understanding and stop ridiculing me or wishing death on me.

> I will be one to admit to missing support-group session and clinical appointments. This is a small community and people talk, so the best place to hide is home, with its challenges of course. My greatest fear is that I saw people on TV (I mean that is the best thing to do since I am practically house arrested) looking like walking corpses and that was really hard. I don't want to end up like that. That's probably my greatest fear. Having to stick-out the gossip in the community is my second most [serious] fear. People who are like us receive free labels: immoral, evil, dirty, etc. Unfortunately, when I get one, my family also do; it is hectic because I am not even sure for how long will I keep it concealed. I told you it flushes out. Loss of dignity is my other fear, there is probably not much of a dignity left, but I will like to die and be buried with respect.

An overlooked potential barrier to ARV treatment adherence is social stigma. Since the beginning of the HIV pandemic, people infected with HIV and AIDS and also the social groups with which they are associated, have been stigmatised by the general population (Greeff *et al*., 2008:322; Rintamaki *et al*., 2006:360). Kleinman (1998:159) notes that if the source of stigma is publicly visible, stigma is deeply discrediting; if concealed from others, it renders the affected person discreditable. In either case, it is internalised as a spoiled identity, a feeling of being inferior, degraded, deviant and shamefully different. Informants, for example, reported that in the eyes of the religious community they were downright sinful or even evil. Thus, the stigmatised person is defined as an 'alien other', upon whose persona projects the attributes that the group regards as opposite to the ones it values (*cf*. Greeff *et al.,* 2008; Kleinman, 1988). From early in the AIDS epidemic, a series of powerful images were used that reinforced and legitimised stigmatisation, namely HIV and AIDS as a punishment (e.g. for immoral behaviour); HIV and AIDS as a horror (e.g. in which infected people are demonised and feared); and, HIV and AIDS as otherness (e.g. in which the disease is an affliction of those set apart) (*cf.* Greeff *et al*., 2008; Rintamaki *et al*., 2006).

Whereas informants would call other disease like tuberculosis or pneumonia by its real name, they would not use the term HIV. Although this influenced their disclosure of the condition, there were cases where the HIV-positive patient, who had indeed disclosed, would still refer to his/her HIV as 'this problem' or 'this other problem of mine'. In the focus-group interviews, HIV was also referred to as 'this thing that exists now', or 'this existing disease', 'bio-slim' and the disease 'with three words or Z3'. This reluctance to verbalise the name of HIV as against willingness to verbalise that of other diseases does signify a difference between diseases in terms of stigma.

At Petrusburg, the stigma brought to the patient by the culturally marked illness label is so powerful that it affects the informant's relationships with significant others and leads to ostracism. Informants discussed some fears of stigmatisation because of their HIV status, which often deterred them from disclosing their HIV status to others and attendance of clinical appointments. These issues are discussed below in respect of family, friends, and the community.

Family

Informants indicated a preference to disclose to at least one significant other (member of an extended family), because it is one of the treatment prerequisites. Throughout the focus-group discussion, informants seemed less likely to disclose their HIV status to their children or parents, and were more likely rather to disclose to other family members not residing with them, such as a brother/sister, aunt/uncle, sister-/brother-in-law. The same tendencies were recorded during the individual in-depth interviews, where the majority of the informants revealed that they had not disclosed their HIV status to one of the members of their immediate families. Reasons related to non-disclosure to immediate family members include: fears of rejection or of negative reactions from the family, or that it would worry family members. The informants’ fears of rejection and of negative reaction were underpinned by stories told regarding other HIV-positive people who were badly treated by at least one of their family members subsequent to disclosure of their HIV status, this resulting in isolation, expulsion from family and being ignored by their family members. With regard to the concern about family, informants felt that they had a responsibility to protect their families from being both stigmatised – in that stigma attaches not only to them as HI-virus infected persons, but also to their families - and moreover worried about their well-being. The latter worry is illustrated by the following view:

> The reason I did not feel so comfortable talking about it to my family, is because they already looked worried, and talking was just going to make the worry worse and eventually not helping any of us. Finally, I spoke to my aunt and she is a good friend of mine. She was extremely supportive and understanding and she listened without judgment.

Friends

While informants did not rule out the importance of disclosing HIV status to friends, most of the informants nevertheless warned against it. Some of the informants did not specifically qualify why they did not disclose. However, from the focus-group discussions and individual interviews it would appear that reasons for non-disclosure were related to fear of gossip, privacy concerns or stigma.

> I don’t mind disclosing my HIV status, but I am forced by circumstances not to. I mean, think, then your very best, close friend carry this heavy secret and s/he decides to share with one of his closest friend, and I am sure he will ask that specific person not to tell, but what? And so the chain unfolds and before you know it, everybody will start acting strange, and then you must know it is because you have HIV.

Community

Most of the informants stated that they had not disclosed their HIV status to the community. This finding somewhat contradicts the role the literature generally attaches to communities in creating an accepting environment for people who have learned about their HIV infection. Reasons for non-disclosure to the community also revolved around fear of stigma. In addition, informants did not view community members as people who could assist them in taking medications. One informant had the following to say:

> They make your life after HIV infection a living hell. I, at one stage, went to see the local councillors with the aim to discuss possible ways to mobilise our small rural community to help fight against stigma. You know, you won't believe this, but he told me how I should not make people take responsibility for my improper, immoral conduct. And he went on, and since that day, I still regret ever doing that. The question I am asking myself is: Where are people with HIV supposed to live?

It was not uncommon for some people with HIV and AIDS to conceal their sero-status from their own families, friends and communities until their health had deteriorated to the point where their illness was visible to families, friends and communities. The stigma and shame that comes with acknowledging HIV and AIDS among the family, friends and the community is one reason why formal health care services are not accessed early on. Disclosure and fears of stigmatisation are reviewed, because most informants indicated that they lived either in a family, with friends or as part of the community, and therefore these concerns (discussed later *cf*. 4.5.2) have increased the difficulty of taking medication, which thus poses a challenge to treatment adherence. Those informants, who admitted non-disclosure to family members because they feared rejection, were precluded from getting help with pill taking from family members (later discussed as a facilitator to ARV treatment adherence, *cf.* 4.5). Knowing that bias and stigmatisation are often consequences of HIV infection, people with high concerns regarding stigma are less likely to disclose their HIV status to others - either out of shame or for fear of persecution. Fear of potential stigmatisation also makes people less willing to be tested for HIV, which in turn interferes with prevention and early-treatment interventions (*cf*. Alonzo & Reynolds, 1995; Holzemer & Uys, 2004). In these and many others cases, the psycho-social aspects of having HIV have a severe impact on an individual's quality of life (*cf.* Wouters *et al*., 2007).

Informants continued to find talking about their HIV status in public and disclosing their participation or involvement in the ARV treatment roll-out challenging, even though the medication was said to prolong life and enhance the quality of life. Those informants who reported finding it difficult to disclose their HIV status mentioned having problems with adhering to a medication regimen that requires consumption at inconvenient times and in less than private environments (e.g. at community gatherings or at home while entertaining company), and furthermore obtaining support from family members for both HIV care and adherence support. Informants who reported having difficulty with disclosing their HIV status cited problems with medication regimen which requires consumption at inopportune times and in less than private environments, such as at community gatherings or at home while entertaining company and attaining support from family members for both HIV care and adherence support. These situations create dilemmas for people living with HIV: they have to weigh the costs of taking their medications against the risk that others could find out that they have been diagnosed with HIV/AIDS.

4.4.1.3 Social support

Informants discussed the twofold nature of social support systems: lack of social support as a barrier to adherence and, when actually in place, as a facilitator of adherence (to be discussed later). What complicates access to social support is non-disclosure (*cf.* disclosure). Perceptions of social support as a barrier are underscored by the following comments.

> I think ARVs are now a substitute for social support. The attitude of the nurses and doctors give one an impression that all you need is ARV, and then you will have a prolonged quality of

> life. I sometimes think I will have a far better prolonged life without ARV, but definitely with support, especially of immediate family and then the broader community. I believe an environment that provide unconditional care and warmth accelerate the process of healing. I really don't mind, I mean, you drink ARV or not, you going to die. But it would be pleasing to die in the family and community that I know it cared and support me in my trying times.
>
> You know, when I talk about support, I feel like crying, because radio, television, church and all over when people are talking HIV care, the first measure or treatment is support. But this message seems to fall on the deaf ear, especially of our own people, black people like me. You won't believe it, neh, but people who care and support us are from outside our immediate community and usually from other racial groupings.

4.4.1.4 Patients' social environment

Social environment as a determinant of health or ill health has of late been receiving attention in literature. Literature reports an association between patients' social environments and their disease vulnerability and mortality risks, independent of individual risks factors (Yen & Syme, 1999:287). The social environmental factors, broadly defined, are critical towards understanding the health and well-being of people. Such factors include the resources that individuals have in their physical surroundings, their perceptions of the quality of their neighbourhoods, communities and health care, and the nature and extent of their personal social networks.

i) HIV and AIDS financial burden

Although all informants were receiving treatment free of charge and social grant, they reported having a degree of concern related to a lack of adequate money for the expenses they might in future have to bear because of a loss of income after HIV infection. They incurred debts to meet ART-specific challenges or for the treatment of opportunistic infections, for meeting travel expenses, for buying nutritious food, and for having access to refrigerators[49]. Informants indicated

---

[49] Studies on ARV treatment adherence reporting good adherence have identified an association between treatment and good nutrition (dietary restrictions). Some of the

living in a resource-limited environment and that they shared everything with the rest of the family. In comparison, people having access to money could simply buy the groceries necessary to take medications as prescribed without having to worry about scraping together a meal in a day. The impact of the socio-economic situation on patient adherence to medication is borne out by the following comments:

> I don't even know what good nutrition means. Not because I have contracted HIV and I am undergoing ARV treatment, but [it] has always been like that. It is such a challenge for me to imagine buying anything out of the ordinary, because the medication demands so. They could have thought of making medication for those people who are wealthy and for us poor people. I eat porridge with cabbage, potatoes sometimes, otherwise porridge with water. I don't know if that is nutritious, but that is how it is. Maybe people getting a grant are dealing with the situation better.

> I receive a government grant because with my health condition I can't work. But that is not only spent on me, but for the rest of the family. I would buy some fruits on the day of grant payment, but after the second or third day, then it's the usual meal. I can't eat and not share with the rest of my family members. That is not how I was brought up. We have to share, no matter how small.

> When I got sick, I initially resorted to self-medication. Time went by and piece jobs [day job, e.g. gardening] got scarce so I could not afford to pay [for] the medication from local pharmacy. My family helped me but it was later just too much to bear with an unstable income. I got very sick and then I was taken to the clinic and after blood tests I was told I have HIV. If I had to go back to him now that I know what caused my problem, it will still be a hidden game, because I don't think I will tell him about my HIV status.

A new challenge that also causes financial strain is the shortage of drugs for those patients already on ARV treatment. It seems that the supply of drugs for

---

antiretroviral medications have strict food requirements for optimal absorption (while AZT, for example, can be taken with or without food, Nevirapine should however be taken with a meal). Informants discussed the difficulty of obtaining the right types of food to eat while taking their medication. Taking pills on an empty stomach increases the risk of gastrointestinal side effects. Some ARVs (e.g. Ritonovir) require refrigeration. Many regimens require twice-daily dosaging.

existing patients is still inadequate. Some of them are being left with an inadequate supply of medication, which, in some cases, has resulted in patients sharing drugs. The financial crisis of the Free State Health Department made headlines in both the electronic media and the newspapers *(*a moratorium in the Free State between November 2008 and February 2009 on ART for patients in the Free State). On account of the said crisis, patients already on treatment may have had to face the possibility of having to stop ARV therapy. Worryingly, this was possible not only in the Free State, but also in other provinces where there have been reports of single-drug shortages (such as d4T in Mpumalanga). The unavailability of a single drug ordinarily means the discontinuation of ARV treatment, as continued use of the other drugs in the cocktail would encourage the rapid and inevitable development of drug resistance. Interruption of therapy for an individual on ARVs has potentially serious negative consequences, namely the development of drug resistance, difficulties in adhering to treatment once the drugs become available, and, an inevitable deterioration in immunological status (i.e. plummeting CD4 count with attendant complications and development of AIDS, depending on the length of the interruption and the patient's prior state of health).

4.4.2 Health care at Petrusburg

4.4.2.1 Availability of services

The moratorium on ART as a result of the financial crisis recently reported in the Free State (Nov 2008-February 2009), increased the backlog of patients in need of treatment and made it harder to reach such patients timeously if and when the drugs were again made available. The public health sector would require increased capacity in order to catch up. In addition, the moratorium weakened HIV-prevention efforts by undermining health-seeking behaviour. Generally, having to wait in queues only to be turned away time and again, deters patients from seeking treatment. It further undermines their confidence in the public health system, and increases the probability that they will resort to alternative therapies (*cf.* complementary therapies). Studies conducted in the Cape Town Metropolitan by Boulle *et al.* (1995) have shown that the delay of even two to three weeks in starting patients with low CD4 cell counts on treatment significantly increases the morbidity and mortality of patients. In addition, there is apparently no system in place for rescuing those patients who are already on ARV treatment, by prioritising their needs over those whose health will not suffer significantly as a result of a short delay in accessing ARV treatment.

> "I was turned away once, because there was not enough for everybody and they promised to give on my next appointment. Luckily I still had some pills left, otherwise I was going to ask this person I know to borrow me some of hers, until I receive mine, and then I will replace them."

> "I must say I am lucky that I finally received my medication. I waited too long, and it was practically during my last days of life that the doctors decided to give the medication. I know of people that I started the screening with, and I can't tell whether they have received the medication as yet. Or do you have to look dead for people to take your health seriously? I don't know. Now here is the challenge: am I going to look at myself dying, while waiting for ARTs when I know I can get some help from the local traditional doctor? (*cf*. complementary therapies) -.....- You can think for yourself."

4.4.2.2 Poor doctor-patient communication

Another theme identified as a barrier to both medication and clinical appointments adherence is poor communication between the patient and the physician. Misunderstandings that might arise from such clinical encounters often reflect differences in culturally determined values, with effects ranging from mild discomfort to non-cooperation and even to a major lack of trust that causes the helping relationship to disintegrate. Core cultural issues are situations, interactions and behaviour that hold the potential for cross-cultural misunderstanding. These include issues relating to authority, physical contact, communication style, gender, age and sexuality (*cf.* De Reuck, 2008; Herselman 1996). Although effective communication between patient and doctor may be problematic in any HIV and AIDS illness episode, inadequate communication has been identified as a distinctive problem confronting HIV and AIDS patients, one resulting from cultural and lingual differences between patients and medical practitioners. Informants reported that, often, communication had to take place in the patient's second or third language, and interpreters (usually nurses) often had to be used. However, informants' limited understanding of the anatomy and physiology of the human body caused problems in explaining basic concepts with regard to HIV and AIDS and its treatment. Although the present study acknowledges efforts made to address this backlog, the lack of terms in the African languages to explain medical procedures, symptoms, etc. make communication difficult even in the presence of a nurse who shares the same cultural and lingual background as that of the patient.

> I think the doctors and nurse sometimes forget that we are not as educated as they are. You must listen to them when they explain the pills to us, then, sometimes, you don't even understand what they [are] saying and when you ask they get upset with you. It's again people being impatient with us. I think it will be better if they explain in our own language. Like now, some people call this pills '*dipilisi tsa AIDS*' ('AIDS pills'), that is 'mos' [indeed] on its own a stigma. No wonder others think they [the pills] are actually spreading the disease, and they are even difficult to swallow.

4.4.2.3 Access to health care

Factors contributing to the delay in respect of accessing formal health care services include reasons related to illiteracy and the assumptions that health care workers bring to bear on the behaviours of those seeking care. In this study, social distance between health care workers and village people, whereby the latter were often assumed to be ignorant, made it difficult for the village people to access the care they needed. Another type of barrier was patients' inadequate knowledge regarding how to take their ART regimes. This comes as no surprise given the informants' levels of education (*cf.* Table 2). While this barrier was not as prevalent as the other barriers described above, some informants cited differences in terms of levels of education as a challenge to their adherence outcome. Perhaps the most extreme case was one involving informants who indicated having taken a drug holiday for days, sometimes weeks, during which they stopped taking ARV medications - because they believed that their bodies needed a ‘rest from pills’, and especially since they were feeling better. This practice is particularly dangerous for patients on ARV treatment, because it gives the virus ample time to mutate and become resistant to the medication. Some of the informants indicated catching up with missed doses by simply taking a double dose. Antiretroviral medication guidelines do not recommend that patients take a double dose of antiretroviral treatment should they miss a dose. Yet, for some reason, informants who are guilty of this behaviour believed that this practice was not only acceptable, but even helpful. When asked about this, they indicated that it was “*common sense, and that we were also advised to make this part of our lives, because it’s going to be a lifetime behaviour”*.

4.4.2.4 Conflicting cultural views

One of the distinct cultural conflicts to emanate from the post-modern western-influenced society is the changing role of the male from that of being the dominant, authoritative figure to one where he accepts instructions from women, especially in institutions of care (i.e. assuming the ‘sick role’). Adapting to the sick role has been instrumental in this regard. Female informants, while being sick and cared for by both male and female medical practitioners and home-based carers, experienced less role conflict than did the male informants who reported that their inherited role had been challenged and to a degree compromised. Comments from the interviews reflect perceptions in this regard:

> “You see in my culture, the Xhosa culture, a man can’t sleep and expect things to happen, he has to make things happen. But this HIV makes you a baby, and that is just unacceptable. I have to provide for my family, that is called manhood among us, the Xhosas.”
>
> Male response

> “Hay! I don’t know if there is much one can do, it’s not like you do it on purpose, it’s because you cannot. You see what makes me mad is being bathed by my wife or children; then they look at my private parts, and there is nothing you can do about it.” Male response

> "For me is just fine, even though I would have liked to do things for myself like I used to. I think my family understand."
>
> Female response

4.4.2.5 Complementary therapies

South Africans negotiate their sickness and healing in a pluralistic medical system. Different therapies are often complementary rather than conflicting, yet there is potential for harmful drug interactions between traditional and biomedical remedies and even between different biomedical treatments[50]. As soon as HIV patients are given biomedical therapy for their sickness, clinic personnel require that such patients discontinue traditional remedies to prevent potentially harmful interactions.

Complementary treatment/therapies.....*There is no incurable disease - only people who think they are incurable.*

> The use of other therapies or treatment outside of the formal western medical sphere's institutions is informed by our parent's philosophy of health, believing that body, mind and spirit/soul are related to health together. In other words, when I am sick, in order to be totally healed, all these aspects should be attended to. I think this philosophy also draws from the belief that ill health is sometimes caused by forces beyond us. So, when I am sick, health balance is disturbed and in order to restore, the medically trained doctor will help me heal the symptoms and the traditional doctors or prophets will facilitate the ritual to appease the ancestors. I don't know what other people think.

Do we have a choice?

> We found this practice here and would probably die and leave it behind. I wanted to keep to the doctor's - I mean from the clinic - advice, but my family convinced me to consult with the traditional healer. They told me my ancestors might have turned their back on me, or they might be unhappy about something I am doing or not doing. They told me I can get all the medication in the world [but] if my ancestors are still upset I will not get healed.

---

[50] As little research has as yet been done on this, the ARV programme has adopted a precautionary approach not allowing any patients to take dual treatments.

“Traditional healers contend that HIV and AIDS is not a new disease, it’s been around much longer than people believe.”

> I saw the witch doctor; you know the ones who will throw bones and tell you what is wrong. I must also tell you that I did not know what was wrong with me then. I had swollen feet and at times could not even walk. I grew up hearing that in such cases somebody might have picked [up] your foot prints, gave them to someone (witch or even witch doctors) for sorcery intention or cause of harm. We spoke and I was not supposed to tell him what was wrong; he was supposed to tell me via supernatural what he see [being revealed] that is causing my feet to swell. I can’t even remember whether we got to a point of him telling me what my problem was, but he bathed my legs, massaged [them] with some ointment and gave me a water mixture to drink. Every Friday, I had to fetch another bottle, and I must say after few weeks my feet got better and I could walk a distance with ease. I got confused and while I was alone I did a lot of thinking. I remember the one afternoon there was a debate on one of the radio talk show and they had traditional doctors and prophets on the show, and they claim they could cure HIV. Traditional healers contend that HIV and AIDS is not a new disease, it’s been around much longer than people believe. So what then? You have, on the one hand, your family preaching the need for ancestral intervention and, on the other, traditional doctors’ claims - confusing. So because I wanted to be cured I agreed to doing the ancestors, beside I had nothing to lose. We went (me and my mother) to see the prophet at church and she asked how many ancestors do I have. She lit three candles and prayed and went home with an appointment for Saturday. We were told to bring a white-feathered chicken or dove. During the second consultation we all went to a small cave for cleansing. After a holy bath, she lit ‘*Umpepo*’ [grass-like mixture], sprinkled the blood of the chicken around and asked my mother to call on our family ancestors, tell them we are here and request their intervention. After the session, she gave me three red candles and asked me to light them on Monday, Wednesday and Sunday and talk to the ancestors via the candles, share problems, especially personal ones. I am just a little disappointed because she never told me what’s wrong with me. It has been done and I am still HIV+, just that they don’t know - at least I hope they don’t. So it’s a difficult one, really.
>
> About the use of complementary treatment, yes, I do understand, because the doctors told us that we have to keep our bodies clean from all other medication or treatment.
>
> You see, my health is not a one-man concern. Usually family will have a say in my management of any health problem. When people come to visit, they always bring something for you to drink or give you some advice on what to do to get well soon. Besides, it is acceptable practice in our community to make use of home remedies -…- the more the better.

Rural patients have recourse only to public health institutions, but because the Department of Health is currently also facing financial challenges, very few clinics are available for ARV roll-out. Screening periods prior to receiving ARV treatment are thus lengthy. So, despite the obvious financial implications to the patient, dual consultation (*cf.* 3.3 sectors of health care) is an integral part of the Petrusburg health care management scene. Although different views have elsewhere been recorded, patients/informants in this study expressed a wish to have access to both forms of treatment in order to maximise their chances of recovery.

For HIV and AIDS and other medical complaints, informants indicated having resorted to both traditional healers (including *dingaka tsa ditaola*[51], diviners and prophets) and western-trained practitioners (public health care institutions like the local clinic and hospital). Informants indicated that while waiting for ARV treatment, they used traditional medicine to maintain their health. Those informants who used traditional herbs said that they had to wait for a long time, because their CD4 count had stabilised. This experience made it difficult for them to stop using traditional medications while on ARV treatment.

---

[51] *Dingaka tsa ditaola* - traditional doctor trained in the use of bones to heal

Table 6: Making headlines in the market

***Miracle Mixer*: natural and traditional supplements**

***1-2-3 You are Up*: symptoms like skin rash, swollen glands, diarrhoea start to disappear and health should improve day by day**

Desperate times call for desperate measures. It is no different with us. I will be the first one to admit, just don't tell the doctors, I am using some of medicines that are sold in the street or pharmacy. What is wrong with helping ARV? Whether they [are] working or helping to improve my quality of life, I mean keeping me healthy and making me strong against opportunistic infection then I will probably give credit to the combination of both - ARV and others - I use. I should also be quick to point that I don't always have money to buy, so when I run out [of other medications] I continue with ARVs alone. I don't know what is others' experiences. For me what is nice about this over-the-counter treatment is, unlike ARV they are not associated to HIV. Even if I buy them nobody will know whether I have HIV or not. They are sold to everybody in the community and the seller will give you a list of all the sickness it can cure and usually HIV is also included. They [are] also easy to drink at home, because at times we can even share with other family members, but they are expensive, and I don't even know whether they are helping. I don't buy myself but every time when a family or friend comes for their second visit, they bring some for me. The decision to buy the specific kind will be based on the story I told them when they first saw me. Once I tell them I have been to the doctor, the question that I always wish they don't ask is, "What treatment are you on?" I mean telling them I am on ARV is giving my status away.

The choice to use traditional medications is underpinned by the reality that informants generally believe that the traditional treatment of illness is deeply rooted in 'African' culture, and that the diviners and *baporofeta* were the health practitioners in their communities for a long time before civilisation came. This worldview serves a functional purpose as it affords psychological healing to 'Black Africans', in that they have the assurance that the supernatural causes of ill health have been addressed, and not only the symptoms (*cf*. Hammond-Tooke, 1998). Informants also pointed out that there are certain diseases that modern medical doctors cannot cure. Diseases like painful legs (causing inability to work), sores (especially around the genitals - *lekgutlo*[52]) can, according to them, best be treated by the *dingaka*. These disease symptoms, which are also related to HIV and AIDS, are attributed to sexual relations with polluted women (*cf*. Kriel & Mapogole, 1998). "*A man who touches an impure (contaminated/polluted) woman, in other words, have sexual relations with such*

---

[52] *Lekgutlo* is illness contracted from having sexual intercourse with an impure/polluted woman.

a woman, may contract illnesses such as makgoma and khutla (lekgutlo); he is said to have fallen into or bitten (go lomiwa) by such a woman, or that she has clogged-up him" (Kriel & Mapogole, 1998:183). *Ho Kgutla/lekgutlo* is normally used with reference to males. Women who are menstruating, who have aborted/miscarried or who are still secluded after having given birth, or who have recently been widowed, are considered to be polluted or impure. In this regard, informants indicated the simultaneous use of traditional and biomedical methods of healing. The methods are seen to be complementary, thus offering the patient a better chance of recovery. This view, if not taken into consideration in the treatment education, can compromise the effectiveness of ARV treatment and the adherence outcomes, especially given the fact that ARVs cannot be taken with any other medication, except those prescribed by the medical doctor.

This finding is consistent with qualitative studies on indigenous healing in southern Africa (*cf*. Hammond-Tooke, 1998; Mabunda, 2001; Pretorius, 2004). This study noted that, in general, minor ailments were treated with home remedies, while more serious complaints were taken to - in no particular order - western doctors, traditional healers and faith healers. Although some traditional causes were mentioned by informants, it is unclear how prevalent these were and how they were related to biomedical aetiologies. HIV and AIDS caused intentionally through witchcraft, though commonly seen as causing sickness especially when multiple misfortunes occur in a family or kin group, were not explored in the present study.

4.5 PERCEIVED FACILITATORS OF ARV TREATMENT ADHERENCE

In the late 1990s and in the early 21st century, some public health officials in the western world believed that Africans, especially those in resource-limited communities, would never adhere to ARV treatment, basing this belief on the high prevalence of illiteracy, poverty and the then current aspects of social realities. According to Heckman *et al.* (1998:140), rural people with HIV reported a significantly lower satisfaction with life, a lower perception of social support from family members and friends, reduced access to medical and mental care, greater loneliness, more community stigma, heightened personal fear that their HIV sero-status would be revealed to others, and, more maladaptive coping strategies – all of which rendering them more at risk of non-adherence. However, recent research has shown that levels of adherence to ART in resource-limited communities are satisfactory (*cf.* Binagwabo & Ratnayake, 2009; Hawkins & Murphy, 2007; Mohanan & Kamath, 2009; Orrell, 2000; Orrell *et al.,* 2003). Amidst growing recognition of the social determinants of health outcomes, social capital[53] is an increasingly important concept in attempting to understand adherence in resource-limited communities (Binagwabo & Ratnayake, 2009:106). The concept was used to attempt to understand adherence to ARV medication at Petrusburg. Although the assumption was not empirically tested, Harpham *et al*. (2002:107) hypothesised that social capital could reduce the impacts of both negative life events (an epidemic) and long-term difficulties (poor health). They further suggested that social capital may also enhance social support, which can buffer the effects of life events on physical health. Whilst the 'bonding' of social capital intensifies existing support networks, the 'bridging' of social capital extends potential opportunities through the support network (*cf*. Harpham *et al*., 2002).

Emerging themes associated with ARV treatment adherence, in no particular order are: *home-based care, disclosed status, health belief and routinisation*[54]*.* The specific social support systems that emerged among these informants were family[55] (both nuclear and extended), treatment buddies/friends, and the

---

[53] While there are a number of definitions that draw upon the seminal work of Gottlieb (1981) and Coleman (1998), and while there is no set definition of the concept in use, this study understands *social capital* to refer to the degree of connectedness and to the quality and quantity of social relations in a given community (*cf.* Harpham *et al.,* 2002).

[54] Routinisation refers to anything that patients do to integrate their medication-taking behaviours with their daily routines (Roberts, 2000).

[55] Although changing in size, structure and function, the African family has persistently maintained its place as the central human social unit. Beyond the traditional African family -

community. Discussion of these themes is limited to informants who have disclosed their sero-status.

4.5.1 Patients’ socio-cultural contexts

4.5.1.1 Home-based care

People with HIV and AIDS are cared for at home by their mothers, wives or sisters because they need to conceal their ill health and their financial problems and moreover, to maintain social distance.

> Well, I am still very quiet about my status to my friends and community. No one in my community knows, because there’s too much of a risk for someone telling, and [my] going to the hospital will certainly make people suspicious. The worst is I know a nurse that works at Bophelong that stays in the neighbourhood. I am scared she will spill the beans; you know women, they gossip. So, for now I prefer to keep it between people who care unconditionally and they are my family.

Increasing numbers of people with symptomatic HIV disease and limited resources for hospital-based care have caused home-based care to be advocated by government intervention programmes. However, few Bolokanang households were adequately prepared to assume this role without additional support. Neither instruction, training nor information was made available to caregivers, not even in relation to the management of relatively simple conditions such as diarrhoea. No guidance on the importance of adhering to universal precautions, nor the means with which to do so, was offered to villagers caring for people with HIV and AIDS. Impoverished households were left to care for the sick and the terminally ill all on their own. The capacity of villages to provide home-based care was severely compromised by the fact that, in recent years, there has been an undermining of indigenous systems of care in favour of the care provided by hospitals and clinics. As a result, village people are caught in

---

whether in the nuclear or the extended form - is a network of people, most of whom are connected by kin or blood relationships, termed the *clanship system*. Patterns of family treatment and care are deeply embedded in this wider kinship system.

something of a double bind; i.e. being reliant on hospital and clinic health care provision, while simultaneously being anxious about how best to access and to pay for it.

4.5.1.2 Family

According to the informants, the families of HIV and AIDS patients did more than merely serve as models of adherence behaviour: family support included reminding patients to take medication and offering financial assistance to cover both travel costs and other needs. Other ways of helping the informants included actually giving them the doses - especially when they themselves were too weak or sick to do so themselves - and encouraging them to keep to the requirements/prescription of the medication regimen. One of the informants who had disclosed her HIV status to those she was staying with said that her family members would inquire about medication intake and would even scold her when she had neglected to take her pills. Families also helped when patients could not go and fetch their pills at the next appointment. Such a family member is also referred to in this context as a treatment buddy. Seeing friends, family members and people around getting sick and/or even dying as a result of HIV and AIDS, was further cited as a powerful adherence motivator, one which made patients commit to taking pills.

> I got really scared when I saw people around me getting sick and, you know, some of my friends are in the state where they are not going to be here for much longer. I mean, they've gotten really thin and they have health problems. So, it scares me when I see that and [it] drives me straight to my pills.

4.5.1.3 Friends/treatment buddy

Living positively with HIV and AIDS, treatment buddies and awareness programmes at Petrusburg

Treatment buddies

In this group we find a reason for optimism in just about any situation, and we understand about the ignorance and fear we've seen in people unfamiliar with HIV. In a conservative community, where people are often afraid to talk about sex, people can't help but be ignorant. As a support-group leader and being HIV-positive myself, I took it upon myself to become educated about HIV and spread the knowledge the best way possible. I must mention categorically that the process has been daunting. I remember the horrible experience I had when I first met with our local councillor. He decided to use a lame excuse for his failure to help me with our group endeavour or initiative. Just one of those things: when you feel up to the challenge, [that] other people will make it their mission to bring you down. You will remember I said something like that during our individual interview. With no support from councillors and important figures in Bolokanang community, I understood the ride was not going to be smooth, but I had my support group and community home-based carer for strength and courage. First challenge: how do I make my status known to the community? We sat with the group, [and] with the help of the community home-based carer , [we] weighed possible implications, from stigma, to ridicule and possible abuse. See, if I was going to die with some dignity, educating the community of Bolokanang, the youth in particular was going to be 'the' best thing. I will like to re-establish a sense of worth and respect. My self-esteem and confidence took a serious knock after diagnosis, and when everybody is after wealth, I would like to leave educational footprints behind.

Awareness programmes

With the community home-based carer, we began public speaking. I spoke to the local lower primary and secondary schools; I could tell them a little about my story and give them a better understanding. At that point they were only spending an hour in the orientation class. So there wasn't much I [had already] covered, so we went to the youth groups and sometimes churches. I had the opportunity to speak at the Free State Life Skills Forum annual meetings and the experience was impeccable. Thank you again for that invite. Talking has been an immensely rewarding experience. Not only is it a kind of healing process, but the feedback I received from people has been amazing. Learning from others and bringing back to our community was also rewarding. Just a pity people in [a] better position are reluctant to support us. Other people have come up and said, "It was great to hear you speak, because I can't speak for myself". Negative reaction is inevitable and has been discouraging, but my support group has been a pillar of strength, I was more talking on their behalf than any other thing. You know, it will probably take them a while to gather some courage to start speaking, and the community['s] negative vibe towards us is not helping. Community apathy and stigma at this stage is a

> challenge for most people living with HIV and AIDS. If we can get that right and create an atmosphere where people can learn to accept you for who you are, I think we should be able to live longer. Challenges of adherence are made worse by the community that is less supportive but judgemental. I almost want to say bring back the days when *ubuntu* was the order of the day. As for me, I guess I am ready to die now.

In this instance treatment buddies are seen as a helping hand. A buddy gives help or support to another person who needs support. The two may be peers, sharing certain characteristics, such as living in the same neighbourhood, both being HIV-positive, both on treatment. This is how informants experienced the role of a buddy:

> They not only offer pills, but also add value to life. If I should compare my immediate family with friends, I would say much as the family is important, you can't help but feel bad about the shame (as a result of stigma) that you brought into their lives. With a friend or buddy you still can reflect on life before HIV, and that gives hope and good memories.

4.5.1.4 Community home-based carer

Community home-based carers are community members who act as a liaison between people in the community and the clinic health officials. They were responsible for some aspects of primary health care and collected household information when requested to do so by public health officials. With the advent of HIV and AIDS, their function has been expanded to include awareness raising, condom distribution, and informing fellow community members about information they have received from clinic health officials. Some volunteers have been instrumental in reducing stigmatisation in the community by visiting and eating with people with HIV and AIDS, or by comforting and giving advice to friends and relatives.

However, at the time of the fieldwork, only one or two out of more than ten home-based carers in Bolokanang were engaged in such activities. Because of other commitments (primarily casual jobs for income), most professed not to have the time to pass on to other community members what they had learned through training. Community home-based care, despite its limitations and the lack of additional support from the government health care sector, has become the most important source of care and support for available to people living with HIV and AIDS in Bolokanang.

> I do not know what has happen to *ubuntu*; I really believe in the good olden days. We would not need ARV, but we would still live longer. By that I am thinking of the unconditional support and acceptance you would receive.

Studies from developing countries (*cf*. Binagwabo & Ratnayake, 2009; Hawkins & Murphy, 2007; Mohanan & Kamath, 2009; Orrell, 2000; Orrell *et al*., 2003) suggest that family and social support can be very effective in helping PLWHA to cope with HIV and AIDS. Families, small or large, are composed of members who have obligations to provide a broad range of support - emotional, social, psychological, or material. Families have structure, functions, and assigned roles, modes of sharing resources, group culture and shared history. Structurally, families can be categorised as nuclear, extended, and joint or created. Families provide or share food, clothing, shelter, security, and social support and are thus able to provide support and to care specifically for people living with HIV and AIDS (World Bank, 1997).

4.5.2 Disclosure

Any person living with HIV and AIDS (PLWHA) has been faced with a major dilemma regarding whether or not to disclose/reveal his/her status to significant others. Practical and psychological difficulties of disclosure exist for individuals living with HIV. Decisions regarding disclosure of HIV status involve anxiety, stigma and shame. According to Sethosa and Peltzer (2005) there are powerful forces working against disclosure. First, there are psychological consequences of disclosure, especially the risk of rejection. Second, there are practical social ramifications especially for those in a sexual relationship (desired sexual encounters may have to be missed), and also for those dependent on significant others (financial or sick care support may be denied). Third, HIV-infected individuals may rationalise that they have a moral responsibility to protect the significant other (from stigma and possible infection).All the informants have disclosed their HIV status to someone, often with mixed results.

4.5.2.1 Reasons for disclosure

Informants disclosed their HIV status for different reasons. Informants, wanting to unburden themselves, reported disclosing their HIV-positive status to family members because they were not able to tolerate the tension all alone. By disclosing, informants expected to alleviate the stressful burden of concealment, to increase emotional and material support, and to facilitate the shared responsibility for safe sex and also self-acceptance of their condition. Those who disclosed to others outside of their immediate family were extremely careful and decided to make disclosure only after giving serious thought to the possible consequences of such action (*cf.* Sethosa & Peltzer, 2005). While some felt very safe discussing their HIV status with the members of their immediate families, others opted or talking to a distant family member.

4.5.2.2 Consequences of disclosure

Non-disclosure of HIV sero-status has its own risks. Concealment of HIV status may be stressful, and the pain of deception and putting others at risk may feel isolating. Non-disclosure removes people who may potentially offer social support, which has been noted to lessen the effects of physical symptoms and depression (Luszczynska *et al*., 2007:40). However, the informants in this study who disclosed, experienced it as a double-edged sword in that disclosure exposed them to emotional distress and to stigmatisation and discrimination from significant others. Such experiences informed the concealment of the HIV status of those who were hesitant to disclose. Informants maintained secrecy of various degrees regarding HIV infection and opted for partial disclosure, revealing only associated health conditions, such as tuberculosis, pneumonia and alcohol-related problems. However, informants reported having experienced difficulty in finding a convincing answer to the queries of others while nevertheless maintaining the big secret. Informants felt that having the families not know about the virus could mitigate stigma from family regarding HIV infection. However, one informant with a high-school education maintained that, *“If the immediate family understands, then there will be no problem to disclose. If they have proper knowledge about the disease then they will treat the patient properly*”.

How it got out:

> I told a friend. At least I thought I could trust her with my secret, but unfortunately soon after telling [her] she could not get fast enough away from me. My sister overheard people talking. Who could have told them? Your guess is as good as mine. My sister brought the news home and I could neither agree nor deny. Tension grew and my mother being the busy body she is, she intervened and that is how she found out. At first things were bad, like horribly bad, but later things got better [to] talk about: *mma ngwana o tshwara thipa ka bogaleng* [a mother holding the sharp end of the sword]. Since then there was no doubt in my mind that I had to live and I know that to be able to live positively with the virus is to make correct choices every day. **-** I do not have the stress of hiding my status from people who love me **-** I have a circle of support around me.

It was not uncommon to hear of people who were rejected by their partners because they revealed their HIV sero-status. Where one partner was on ART, they resorted to pill hiding, occasional skipping of medications and failing to keep clinic appointments for refills or review, so that their partner or significant other would not find out that they were on ART.

Sethosa and Peltzer (2005:30) found social support, especially family support, to be significantly related to disclosure of HIV status in South Africa. On account of disclosure, informants received social support both in the form of emotional support (caring and reassuring companionship from friends and family) and informational support (i.e. advice and guidance about HIV and ART). Luszczynska *et al*. (2007:38) have found that people receiving more support are less likely to suffer physical symptoms, have better immune status and lower morbidity, which, in turn, results in less activity limitation.

4.5.3 Routinisation

Becoming scared and therefore making a commitment to take ART pills each day was cited as an important facilitator of adherence. *Routinising* the medication regimen was a way of fulfilling this commitment. Some informants tied their morning doses to waking up; others took their pills with meals. Although, because of individual contexts, this was not the most favoured routine (especially for those with irregular waking hours and those who were not sure where their next meal would come from), these strategies proved successful. Routinisation was easier for those informants with predictable daily schedules than for those who had unstable lives. Those who were at home every day had a clock and a private space to take their pills; the adherence behaviour of those who would be looking for a day job would be challenged because of a lack of reminders and private space. For many informants an important aspect of routinisation was to carry their medications and reminder clocks with them when they were away from home. During our focus-group interview, which was held at a local community hall, it was interesting to see informants – who had brought their medication with them, requesting time to take the pills. It is important to note that the environment was conducive to take pills publicly in that all those present knew one another HIV status.

4.5.4 Patients' beliefs about treatment

Some informants stated that they made great efforts to take the ARV medication as directed because they believed that the pills were making a noticeably positive difference in their health status. The most frequently stated benefits of ARV medication adherence were: HIV management (reducing HIV-positive patients' viral loads), better overall health, living longer, and gaining weight. These findings support those of Wenger *et al.* (1999), who noted that patients' beliefs about the illness itself and about the effectiveness of the medication were predictive of adherence. A good level of understanding of HIV by the patient, a belief that ART is effective and that it does indeed prolong life, and recognition of the fact that poor adherence may result in viral resistance and treatment failure all impact favourably upon a patient’s ability to adhere. Conversely, a lack of interest in becoming knowledgeable about HIV and a belief that ART may be potentially harmful do adversely affect adherence.

The adherence and non-adherence trends found in this study are comparable to those of other studies in resource-limited settings. The data suggest some of the facilitators of adherence to be: acceptance of HIV status and disclosure; self-motivation to adhere to medication (self-efficacy and the ability to take and adhere to ART); belief in the efficacy of treatment (ARVs); a patient’s pre-treatment health state; perceived availability of social support; an effective adherence support group (treatment buddies); and, a desire to stay alive for the sake of others (specifically children). Factors found to constrain adherence were: non-acceptance of HIV status; non-disclosure of one’s HIV status and of being on ART; perceived lack of social support; stigma; logistics; and, treatment-related costs. While concerns about long waiting times at the health facilities and lack of food were admittedly brought up during the interviews and discussions, these were viewed as inconveniences and were thus not necessarily linked to sub-optimal adherence. In addition, information on the Department of Health moratorium suggests that the erratic availability of ARVs at roll-out sites and some health care facilities could have an impact on patients’ ability to adhere to ART.

4.6 DISCUSSION

Antiretroviral therapy has been reported to affect viral replication positively; to reduce morbidity; and moreover to provide people who are HIV-infected with prolonged, quality, healthy lives (*cf*. Mannheimer *et al.,* 2005; Wouters *et al*., 2007). Although ARV treatment can improve immune status and decrease mortality, the efficacy of the drugs depends on patients’ adherence to recommended dosing regimens. A lack of adherence is related to many factors - including the complexity of and the adverse side effects of ARV treatment - but it also depends on patients' self-regulatory beliefs, the supportive behaviours of others and patients' beliefs about the disease (*cf.* Luszczynska *et al*., 2007; Orrell, 2005; Orrell *et al.,* 2001).

According to Becker (1985:539), patient non-adherence interferes with public health and health care providers' efforts in a variety of ways. First, it disrupts, neutralises or nullifies the benefits of the preventative services offered. Second, it involves the patient in additional and unnecessary diagnostic and treatment procedures, thereby generating further costs and possible health problems caused by the treatment. Third, it negatively influences the client's views about the services received. Some would even argue that poor medical outcomes resulting from non-adherence account for most of the general dissatisfaction currently expressed in respect of health care delivery in South Africa.

Proper adherence is a necessary component of ARV treatment. Continuing the process of ARV roll-out, and optimising treatment outcomes for people living with HIV and AIDS in a multicultural South Africa, requires careful attention to the socio-cultural context (patients' explanatory models, their living conditions, and their individual health beliefs and perceptions, etc.) surrounding self-care. Qualitative research can be harnessed to identify culturally specific determinants of adherence in new settings, and can be used to lay the groundwork for adherence counselling and intervention strategies. While many of the diseases that currently plague the human species are preventable and/or treatable, successful HIV management requires that the individual should undertake the recommended preventative action. Similarly, successful treatment often depends upon the extent to which a person's behaviour coincides with medical or health advice (Becker, 1985:539). Unfortunately, data indicate that considerable non-adherence occurs whenever some form of self-administration or discretionary action is involved, usually outside the clinical context, and within the patient's living context *(cf*. Dean, 1981, Hunt & Arar, 2001; Reynolds *et al.,* 2004; Roberts, 2000; Wiebe & Christensen 1996).

The results emanating from this study confirm several important facts related to understanding adherence, and moreover shed additional light on other areas of patient social interaction that might facilitate/hinder adherence to ARV medication. The findings clearly demonstrate just how challenging it is for HIV and AIDS patients to adhere to ARV treatment. Yet, some of the barriers to adherence that informants face - such as those related to inadequate knowledge about their regimens - can potentially be overcome via both more and better health education regarding ARV regimes. Health literacy is an important predictor of treatment adherence, particularly in low-income and low-literacy populations (Christensen, 2000; Christensen & Johnson, 2002; Kalichman *et al*., 1999; Orrell, 2005; Orrell *et al.,* 2001; Osterberg & Blaschke, 2005; Roberts, 2000; Rosner, 2005). Adherence interventions are vitally necessary in this population to help accommodate individuals who have difficulty in reading and understanding medical instructions.

Provision of information about the nature of illness and its treatment, has, at a fairly abstract level, generally not increased adherence. Other studies (*cf*. Becker, 1985; Hardon *et al*., 1995; Helman, 2000; Kleinman, 1980) have shown that the aspect of medical care about which patients express the greatest dissatisfaction is the amount and form of information they receive from health care providers. Medical jargon is often misunderstood by patients. It is also worth noting that as much as one half of what the health providers say is often forgotten almost immediately by the patient. Written instructions should thus be provided whenever possible to reinforce oral communication. Furthermore, people have experienced or heard about the potential adverse consequences of different medications. ARVs are no exception. Individuals are continually exposed to mass-media controversies, contradictions, and often reversals with regard to public health and medical recommendations (e.g. the ongoing debate about the negative side effects of ARV treatment). While literate people might understand that these debates provide more information prior to embarking on medication, the debates might pose a challenge to those people who are less educated, causing the latter to opt for a literal meaning of the debates. This could ultimately result in people doubting the efficacy of ARVs.

In addition, adherence support should be provided to patients who have difficulty in navigating the health care system. Although informants indicated facing more challenges with regard to non-adherence resulting from having limited resources, research done on correlates of self-reported adherence has shown that the level of adherence in resource-constrained countries is at least as good as that in resource-rich settings and that the rate of virological suppression is equivalent or better (Hawkins & Murphy, 2007:1041; Orrell, 2005:172; Orrell *et al*., 2001:483; 2003:1371). However, the lack of access to a consistent supply of ARV medications, together with financial barriers that may cause treatment to be interrupted, appears to be the primary obstacle to adherence in resource-constrained settings. Oyugi *et al*. (2007:968) emphasise the importance of financial stability and a sustained drug supply. Clearly, the ability to remain on therapy is important towards ensuring optimal clinical outcomes in HIV. As illustrated both in this and other studies, treatment interruptions caused by external factors, such as an inability to sustain drug availability, may constitute more of a risk to success of therapy in resource-constrained communities than would an individual's own level of adherence (*cf.* Hawkins & Murphy, 2007; Orrell, 2005). Addressing the issue of 'non-adherence' may therefore require somewhat different approaches to those practised in the resource-rich areas.

Previous research has revealed that a relationship exists between adherence (both clinical appointments and ART) and either perceived support (*cf*. Godin *et al*., 2005), or satisfaction with support (*cf*. Catz *et al.,* 2000). This study suggests that this relation may be mediated by finding means of destigmatising HIV in order to instil self-belief in the infected. Luszczynska *et al.* (2007:41) found that patients with strong optimistic self-beliefs about their ability to cope with adversity were more likely to find positive changes in their social relationships, to perceive improved personal strength, and to appreciate their lives. Having such beliefs, in turn, has been recorded as a predictor both of better adherence to recommended treatment and of enhanced physical functioning (Godin *et al*., 2005:498).

In line with previous research, I offer some concluding comments with regard to care and support for people living with HIV and AIDS, their families and communities. It is, for example, important to build upon local household and community responses when initiating programmes and making interventions. Generally speaking, people with HIV and AIDS, in this study, were provided with support and care by household and family members; where such help was denied, this was most usually a result of efforts to limit the visibility of the condition, and a consequence of the stigma locally linked to AIDS. The results of this study suggest that urgent action is thus required to reduce the levels of stigmatisation and discrimination currently being levelled at people infected with HIV if, that is, support and care are to be provided more overtly.

The findings of this study also demonstrate how concerns about social stigma could influence not only patients' psychological experience of HIV infection, but also their medication practices and, consequently, their adherence to treatment, clinical appointment and health outcomes. This finding, which associates concern for HIV-related stigma to poor adherence to antiretroviral regimes, is consistent with previous selected studies on social stigma concerns, and HIV medication and clinical appointment adherence (*cf*. Alonzo & Reynolds, 1995; De Reuck 2008; Holzemer & Uys, 2004; Rintamaki *et al*., 2006; Roberts, 2000). In order to optimise adherence, most health literature seems to favour disclosure by persons living with HIV and AIDS. But it could well be that disclosure is not always desirable. Disclosure is stated to be patients' greatest concern about being diagnosed with HIV (Sowel *et al.,* 1997:12) as it leaves the choice of either disclosing or concealing his/her status squarely with the infected person. However, it appears that both disclosure and concealment could result in disadvantages, like social isolation, diminished access to health and social services, and a diminished sense of personal control. Advantages comprise going for voluntary testing and counselling (VCT), accessing group therapy, care, treatment and support services, which all play a crucial role in optimising ARV treatment adherence. Fear of contagion, coupled with negative, value-based assumptions about people who are infected leads to high levels of stigma surrounding HIV and AIDS. Factors that contribute to HIV and AIDS stigma are: HIV and AIDS are life-threatening, and elicit strong reactions from people; HIV infection is associated with behaviours – e.g. promiscuity, drug addiction, prostitution - that are already stigmatised in many societies; inaccurate information about how HIV is transmitted creates irrational behaviour and misperception of personal risk; HIV infection is often thought to be the result of personal irresponsibility; and, religious and moral beliefs lead some people to believe that being infected with HIV is the result of a moral blunder (such as promiscuity or deviant sex) that deserves to be punished.

In 2003, when launching a major campaign to scale-up treatment in the developing countries, the World Health Organization claimed that as AIDS becomes the disease that can be both prevented and treated, attitudes will change, and that denial, stigma and discrimination will rapidly be reduced (WHO, 2003). It is difficult to assess the accuracy of this statement in that levels of stigma are hard to measure and they manifest themselves differently across countries, communities, religious groups and individuals. Stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole. On a national level, the stigma associated with HIV can deter governments from taking fast and effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care. Regarding the HIV-related stigma, UN secretary-general Ban Ki Moon has said:

> “Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about

> it, or taking easily available precaution. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world".

HIV and AIDS-related stigma is not a straightforward phenomenon as attitudes towards the epidemic and towards those affected vary massively. Even within one community, reaction to HIV and AIDS will vary between individuals and groups of people. Religion, gender, sexuality, age and levels of AIDS education can all affect how somebody thinks and feels about the disease. AIDS-related stigma is not static; it changes over time as infection levels, knowledge of the disease and treatment availability vary.

In addition, the informants in this study also mentioned that the likelihood of non-adherence is increased by regimen complexity. Research on treatment adherence among most patients with chronic diseases suggests that increased complexity of medication regimens is associated with decreased adherence. In this context, regimen complexity refers to the number of doses taken per day, the number of pills per dose, the number of different medications taken, issues of medication availability, patient forgetfulness, and the desire simply to have breaks from the endless routine of taking pills. Adherence is further complicated by the fact that doses remind them of being HIV-positive, that there are a number of food-related restrictions or requirements, and that there are a number of special fluid-intake requirements. Clearly, ARV regimens can thus, at times, be extremely complex, in that they involve many doses, many pills, and, often, one or more medications that cannot be taken with food. In response to these challenges, studies on medication adherence in resource-challenged settings, and among people with a low literacy level suggest that regimens can be made less complex by

(1) avoiding the routine prescription of non-essential medicine or unnecessary doses or variations in scheduling;
(2) emphasising the necessity of adherence to particularly critical aspects of treatment (i.e. prioritising the regimen);

(3) breaking the treatment plan into less complex stages that can be implemented sequentially; and
(4) minimising both inconvenience and patient forgetfulness by matching the regimen schedule to the patient's regular daily activities (i.e. tailoring the regimen) (*cf*. Becker, 1985; Calmy *et al*. 2004; Christensen, 2000; Christensen & Johnson, 2002; Kalichman *et al*., 1999; Murphy *et al*., 2003; Orrell, 2005; Orrell *et al.,* 2001; Osterberg & Blaschke, 2005; Roberts, 2000; Rosner, 2005; Stone, 2001).

The other biggest obstacles to adherence were found to be those caused by a scarcity of resources, for example money for transport to the clinic and food for self and family. Such obstacles had to be overcome by borrowing money or going without food in order to maintain good health through excellent adherence. But the interviews revealed that maintaining good health was not an end in itself. Ill health placed a burden on others, and placed the individual at risk of losing the support of others - support that, in times of good health, was critical towards overcoming hardships distinct from HIV and AIDS. Good adherence and good health reduced the frequency of calls on the goodwill of others, which made it more likely that, when future need arose, potential helpers would be willing to help. Poor adherence, on the other hand, was perceived as letting down helpers and this by raising the spectre of ill health, caused individuals to question whether family and neighbours might abandon them or downgrade their needs if they became burdensome. These findings are consistent with those of numerous recent studies that examined and documented correlates and predictors of ARV treatment adherence (*cf*. Bharat, 1995; Binagwabo & Ratnayake, 2009; Booysen, 2005; Orrell *et al*., 2003; Roberts, 2000).

In 2004, when the South African government implemented the public-sector ART programme, it was acknowledged that adherence to medication was crucial to the success of ARV treatment. In consequence, the treatment buddy system for people on ART was initiated, the aim of the system being to complement the overburdened health care institutions by using both the families and the communities to enhance patients' adherence to a lifetime of treatment. In this study, social support surfaced as the most frequently referenced ARV treatment-adherence facilitator. The most frequently reported facilitators of adherence included help from others (specifically families and treatment buddies). The emergence of this theme also lays the groundwork for adherence-intervention efforts. While family members were frequently referred to in this context, the community was not. The informants achieved success with ARV medication adherence through personalised management of the regimen, the self and the environment. These findings are consistent with those of other qualitative studies that have found that adherence is fostered when patients believe in the efficacy of the medication (*cf.* Bartlett, 2002; Murphy *et al*., 2003; Schilder *et al.,* 2001), when the doctor-patient relationship is good (*cf*. Helman, 1990; Kleinman, 1980; Powell-Cope *et al.,* 2003), and when medication taking is a priority in their lives (*cf*. Malcom *et al*., 2003). Lastly, Edwards (2006:680) notes that social relationships and affiliations have powerful effects on physical and mental health and well-being. While stigma emerged as a major barrier to ARV treatment adherence, social support surfaced as the most frequently cited facilitator. These two themes are however at odds with each other in the case of certain individuals. Informants reported having a difficult time disclosing their HIV status, which could lead to problems such as taking pills in public and obtaining support from family members for HIV and AIDS care and adherence.

Medication beliefs of patients with a specific medical condition have been associated with non-adherence to the drugs used to treat the condition. Research suggests that many people have a fairly negative view of medicines in that they perceive them to be generally harmful substances that are overused by doctors (*cf.* Gatti *et al.,* 2009; Horne, 1999; Horne *et al*., 1999; Phatak, 2006). ''Negative perceptions of medication in Horne (1999:492) view are ''often associated with the notion that the dangerous aspects of medication are linked to their chemical/unnatural origins and that complementary treatments are perceived to be more 'natural' and therefore safer''. Such general perceptions of a class of treatment are likely to inform treatment preference and even pathways to care (*cf*. sectors of health care, complementary therapies), while subsequent adherence to treatment is likely to be more strongly influenced by the beliefs about the specific medicine prescribed to them (*cf*. Gatti *et al*., 2009; Phatak, 2006).

According to Horne (1999:491), ‘’a new view of health care is emerging in which patients are expected and encouraged to take a more active role in their health care and in decisions about treatment. However, at present, we know little about either how patients take decisions or about the origin of preferences for one treatment over another. Such information is essential if we are to help patients take informed, rational decisions regarding the management of their illness and for the development of interventions that may increase adherence. Previous attempts at understanding how patients take decisions about their treatment have examined patients’ beliefs about their illness, while ignoring the interplay that exists between patients’ illness and their perceptions regarding treatment. It is likely that a twofold structure – one in which both the patients’ perception of the problem (beliefs about the illness) and the possible solutions (beliefs about treatment) are considered in parallel - would lead to a more useful model’’.

This study has revealed that informants overcome economic obstacles by begging and borrowing money from friends and families. Informants, who did not have the money to buy food, would take their medications without food even if this would increase the risk of side effects, and they would walk to the health care centre, which is fortunately within walking distance.

The global HIV and AIDS pandemic has triggered responses of compassion, solidarity and support. Other responses, however, have associated the disease with stigma, ostracism, repression and discrimination because many HIV-infected individuals are rejected by their families, loved ones and communities. Ignorance, fear and denial have worldwide denied PLWHA access to treatment, services and support, and have made HIV prevention and treatment more difficult. Fear, stigma and discrimination have undermined the ability of societies to protect themselves and provide support and reassurance to those who are infected. This study argues that care and support, both medical and emotional, can help HIV and AIDS patients to lead fulfilling lives.

The study findings suggest the importance of social capital – trust, co-operation, reciprocity and sociability – in maintaining adherence. The study argues that social capital also explains patients' fear of stigma, because stigma isolates people from social relationships that could improve their chances of survival - hence the strenuous efforts to avoid stigma, even at potential long-term costs to the individual. Adherence preserves social capital by protecting the relationships required for survival in settings of poverty. This may be what patients are referring to when they tell us they have 'no choice' but to adhere. The study however notes that these findings may not be applicable to all resource-constrained settings, and further calls for research on social capital in order to guide interventions that will both maintain adherence and sustain treatment effectiveness. Furthermore, since acceptance of HIV status (*cf.* 4.2), disclosure (*cf*. 4.5.2) and gender (*cf*. 1.4.2.2) were found to be the main emerging themes in the qualitative data, further studies are needed to explore these variables in greater depth. Programmes targeting men to inform them about HIV-related issues should also be developed. This would help increase the enrolment of men in ART programmes, help them to better understand the gender issues around HIV, and mobilise them to become protectors and supporters of women in the fight against HIV.

Furthermore, while it is important to note that the barriers to and facilitators of adherence found in this study do provide a rich understanding of the complexities of adherence for some HIV-positive patients beyond the clinic or places of care (e.g. Hospice), several limitations of the study should also be noted. Firstly, these findings should be considered to be preliminary and by no means exhaustive. The results are based on a small sample and the themes that have been analysed are limited by the extent to which individuals disclosed the issues that were relevant and important to them. There may still be additional barriers and facilitators that were not mentioned by the informants interviewed. It is quite possible that other types of patients (e.g. homeless individuals or individuals who are well off and living in urban areas) face different barriers and facilitators. Future studies should explore these and other possibilities.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

The primary goal of this study was to explore the socio-cultural contexts of people with HIV and AIDS who are on ARV treatment. This was done in order to understand the multiple ways in which people at Petrusburg experience and deal with their ill health. An attempt was made both to identify and explicate the complexities of the processes involved and further to demonstrate how these generally affect not only the treatment outcomes, but also the experiences and perceptions of the sickness (HIV) itself and of those who are the carriers or, often, the perceived carriers of these sicknesses.

This study argued that, in order to arrive at a broad comprehension or interpretation of adherence – one involving a search for meanings, a teasing out of hitherto unheard voices and hidden connections - we need to go beyond merely interpreting the self-reported cases of adherence, which is often ideally presented as the obvious and prevalent mode of inquiry. I thus attempted to relate the interpretation of self-reported cases of adherence to the dynamics and limitations current in the health care system and the broader macro socio-economic context in which the sick live out their daily lives.

The risks of contracting HIV are structural. So, too, are the risks of non-cure and death. Despite having access to 'free' medication and health care, the burden to the poor in South Africa of sickness and the social and indirect financial costs related to this are immense. The marginalised are further also more likely to experience social stigma and increased marginalisation as a result of illness. The academic, specifically anthropological contribution of this study may be outlined in a number of ways. Firstly, this study underlines the fact that it is important that practitioners both acknowledge and display sensitivity regarding the socio-cultural factors in medicine. It is a given that all people will at one time or another fall ill. This study has argued that the impact that any disease has on a patient is a very personal and often unique experience. During every phase of ill health, many issues emerge in the affected person's mind, thus compelling him/her to perceive, evaluate, and guard against further deterioration or complete loss of health. The form the recovery plan assumes is often subjective and sometimes even decidedly idiosyncratic. Beyond the individual, and in response to such episodes of ill health, each community/society and social group – such as the family – have their own unique ‘language’ of distress, and their own complex idiom by which ill or unhappy individuals make other people aware of their suffering. The precise form of such pain behaviour is largely culturally determined.

Secondly, this study addressed the importance of clearly conceptualising and distinguishing related concepts applied during the health care delivery process. In studying the relationship between culture and conceptions of ill health, the study indicated that people from different societies have different ways of explaining ill health, patterns of health seeking, and the causes and presentation of health problems. This finding resonates well with the following conclusions and clinical lessons drawn from anthropological and cross-cultural studies on notions about episodes of ill health and their treatment: (1) universal conceptualisations of ill health are limited; (2) the meaning, experience and expression of ill health vary as a function of culture and social contexts; and (3) standard symptoms in one context may be experienced and interpreted differently in another context. The above conclusion suggests that contextual variations exist in the following areas of ill health: meaning, perceived causes, onset patterns, symptoms expression, the natural history and severity of the disease, and appropriate treatment for the conditions. These variations have important implications for understanding clinical activities, such as conceptualisation, assessment and treatment. Thus, coming to some understanding of how people at Petrusburg experience illness requires that one not only focus on culture, but also on the limitations caused by context-specific hardships.

An explanatory model was used to explore the causes, the symptoms and the experiences of HIV and AIDS, and ARV treatment at Petrusburg. Informants’ (patients’) knowledge of the aetiology of HIV and AIDS were shown not to be in alignment with biomedical aetiologies. Stigmatisation attitudes that view HIV and AIDS as a moral disease are generally prevalent. This has been found to influence perceptions of illness, while also negatively influencing health-seeking behaviour, and, ultimately, poor clinical appointment adherence. Although the exercise was limited to patient's narratives, traditional aetiologies of HIV and AIDS were explored and it was found that although perceptions of cause can be based of traditional beliefs, patients use ARV in addition to more general traditional remedies. Support structures were investigated, and the study revealed these to be crucial in influencing the sick person's ability to act upon his/her knowledge to effect a cure and get well. The ethnography showed social capital to be crucial in managing sickness, health and clinical appointments.

In retrospect, the study found that the explanatory model did not allow for consideration of the effects of individual relations of power. This is clearly a weakness both of the model and of how it was applied by Kleinman. My research at Petrusburg suggests that the contextual causes and constraints of sickness are as important as the cultural beliefs. Furthermore, the first aspect of Kleinman's explanatory model concerns the symptoms and signs by which the illness is recognised. HIV and AIDS are associated with many physical and emotional problems. What makes the disease complex is that signs and symptoms vary from one individual to the next. When first infected with HIV, one may not have signs or symptoms. Even if one does not experience HIV symptoms, the virus is actively multiplying, infecting and killing all cells of immune CD4+T cells that are the immune system's key infection fighters. As a result, the health of HIV sufferers deteriorates slowly and symptoms are experienced only after a relatively long period of time before treatment is sought. The symptoms of HIV, as identified by the Department of Health and communicated in their posters and leaflets to be found in the clinics are depression, loss of appetite, loss of weight, non-stop coughing, tiredness (fatigue), thrush, lipodystrophy, sinus infection, burning and tingling of the feet and hands and swollen glands. These are non-specific symptoms and could also be experienced by someone who simply has flu or tuberculosis. In many cases, health care practitioners take precautionary measures and advise people to get tested for HIV. With HIV being a highly stigmatised condition that has general symptoms similar to those of *ho kgutlwa* (illness [sores around the penis] contracted from having sexual intercourse with an impure/polluted woman), some people with such like disease, might, on the one hand, think that they are experiencing the symptoms of HIV and thus delay or even avoid seeking early treatment for their particular symptoms; on the other, they might resort to self-medication, which also delays health seeking and early diagnosis. It would seem that in the case of HIV and AIDS signs and symptoms do not prompt sufferers to realise that they have a health problem.

Whereas it is understood that biomedical treatment is necessary to manage HIV in the case of the individual, it is nevertheless also emphasised that patients' contextual realities (structural hopelessness and the poverty-and-illness trap) have to be addressed at the broader societal level and not blamed on infected individuals' so-called irresponsible or irrational behaviour. Correct knowledge does not necessarily result in correct action. Although informants knew that HIV could be managed with treatment, they still delayed presenting at the clinic as they would then have had both to face and to tell others about their condition, here a decidedly stigmatised condition. I am however careful not to attribute all the experiences and actions of those who are ill to socio-cultural contextual limitations and so perpetuate the perception that patients are passive actors in health care. Patients do have agency and do take decisions according to the constraints amidst which they find themselves. This finding is a significant one for educational and awareness programmes.

The above discussion has pointed to the relative usefulness of Arthur Kleinman's explanatory model, but has argued for a more inclusive approach that combines individuals' explanatory models with the socio-cultural challenges and barriers both to health care and to health. The biomedical models are useful towards understanding not only illness and responses to illness, but also to patterns of health seeking. Yet they can be incomplete if used in the analysis of socially induced diseases such as HIV.

A third aspect addressed in this study is that health programmes that fail to recognise and work with local beliefs and practices generally fail to reach their goals. Similarly, the ARV treatment roll-out needs to take cultural beliefs and behaviours into account in order to understand why the treatment is effective or not effective and then decide what to do about it. Health, illness and treatment are defined, labelled, evaluated and acted upon in the context of culture. If you wish to help a community improve its health, you must learn to think like the people of the community. Before asking a group of people to adopt new health habits, it is wise first to ascertain what the existing habits are, how these habits are linked to one another, what functions they perform, and what they mean to those who practise them. This study contributes to our understanding of HIV, AIDS and ART in resource-constrained communities, and it illustrates how meanings can shift and change, thereby re-emphasising the importance of contextually relevant interventions.

Fourthly, this study has methodological value. It underscores the necessity of building rapport, particularly when dealing with issues that are both emotional and sensitive in nature. It also raised ethical questions around the duration of fieldwork with people who are HIV+ and whose sero-status is undisclosed. Informants experienced that being ill was not a problem in terms of attitude; it was looking ill that changed people’s attitudes. My regular visits were somehow experienced as a trigger for gossip; follow-up questions and probes were experienced as re-opening the healed wounds and succeeded in doing more harm than good. While I grew personally and academically, the study was also an emotional journey and possibly a test of character, especially my ability to persist irrespective of the pain and, in many instances, informants’ hopeless living conditions about which I could do nothing.

In line with the findings of Vecchiato (1997:185) on contextual relevance, this study also concludes that “in particular, the identification of the socio-cultural determinants of ‘patient adherence’ has proved critical in the success or failure of ARV therapies”. The socio-cultural determinants this study identified include health beliefs, perceptions of severity, aetiologies and degree of medical knowledge. The similarities with Kleinman’s notion of the explanatory model are thus evident. Although he does not focus on these in his analysis, Vecchiato (*ibid.:*195) does mention that “practical, financial, social, structural and geographical considerations” do also play a role in the management of illness.

The findings from the Petrusburg study suggest implications not only for current and future ARV treatment roll-out practices, but also for research and for health policy. The literature contains many papers that address the importance of adherence and also the potential consequences of non-adherence. Persons living with HIV and their caregivers are aware of the importance of adherence and use a wide variety of strategies to enhance antiretroviral therapy adherence, though with varying degrees of consistency and success. Given the unique socio-cultural context of each individual on ARV roll-out, there are no easy answers regarding how to optimise adherence. No one single case of adherence can be used as a predictor for another. As noted, adherence is the result of an interaction of many complex entities (e.g. medication, personal, economic factors, etc.). Informants - who indicated having had success with adherence - refer, for example, to the management of regimen in relation both to self and the environment. This study broadens the patient-focused approach of predicting treatment adherence/non-adherence by incorporating factors of the socio-cultural context. Adherence assessment is most successful when conducted in a positive, non-judgmental atmosphere. Patients need to know that their provider understands the difficulties associated with adhering to an ARV regimen. Within a trusting relationship, a provider may learn what is actually happening with the patient’s ARV medication regimen, rather than what the patient thinks the provider wants to hear.

A conclusion from this study is that there is a need for further context-specific research on household and community responses to ill health and the implications of ill health on the family social structure. Such work would, in all probability, demonstrate more comprehensively the huge burden of illness for households in resource-constrained communities and add weight to international calls for increased investment both in disease prevention and pro-poor curative health services. International research efforts also need to develop a common illness cost-and-impact methodology to allow more meaningful comparisons of the economic burden of illness across settings and diseases.

Interventions for successful adherence are an ongoing effort, not one-off events. Studies by Orrell *et al.* (2001:484) suggest that adherence rates decline when patient-focused interventions are discontinued. Therefore, positive reinforcement is extremely important at each clinic visit or contact. This entails reinforcing what the patient has done well and assisting the patient in identifying problem areas that need to be improved. Whenever possible, share positive information about the patient's health, such as improvements in quality of life, CD4 cell count, and viral load, to encourage a high level of adherence. In order to improve compliance with prescribed regimens, the patient must be involved in the decision-making process and be fully supported by professionals. This requires a multidisciplinary team to allow enough time to educate patients, listen to their fears and anxieties and deal with these as far as possible, and then to provide the support the patients need.

Another approach to improving adherence involves tailoring the medication to the patient's lifestyle. It is probably pointless to expect patients either to adjust or acclimatise to the treatment regimen. For example, for some patients, specific dosing intervals may improve treatment adherence. Reducing the number of doses may simplify treatment regimes and is especially important when such regimens include multiple medications. By comparing patients' and providers' goals, strategies and evaluations, a better understanding could be developed of how recommended behavioural changes are variously understood and applied by each group. What is required is sustained community mobilisation aimed at mitigating stigma and discrimination in an effort to create an environment in which people can disclose and take their ARVs without fear of discovery.

Some policy-related issues or points for discussion arose from this study. In line with recent reviews on the impact of HIV and AIDS on patients' socio-cultural contexts, this study has concluded that the social impact of the disease is enormous and that immediate action is required to improve control - particularly through better-targeted anti-HIV and AIDS campaigns - so that the poor may gain access to prevention (and treatment) measures. A first such issue, although not an objective of this study, would be to improve coverage of preventive measures, particularly among the poor. Recurring indirect high hidden costs of HIV and AIDS would strongly justify such efforts.

A second issue for discussion, and one moreover also recommended by the World Health Organization Commission on Macroeconomics and Health would be to advocate for far more investment in close-to-client curative services so as to expand access to treatment and reduce the direct and indirect costs of illness to households.

A third issue is that health-policy research and -debates need to be broadened because, even if health services are improved, they cannot protect households from all illness-related costs, specifically expenditure on non-medical items and indirect costs. Can governments, working alongside NGOs and community-based organisations, develop innovative social security measures to help protect households from the hidden costs of HIV and AIDS? These are questions for future research and debate across communities.

LIST OF REFERENCES

Abdel-Fattah, E.D. & Huber, G.L. 2003.

Individualism vs collectivism in different cultures: a cross-cultural study. *Intercultural Education,* 14(1): 47-55.

Abosede, O.A. 1984.

Self Medication: an important aspect of primary health care. *Social Science & Medicine,* 19(7): 699-703.

Alonzo, A.A. & Reynolds, N.R. 1995.

Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Social Science Medicine,* 41 (3): 303-315.

Ammassari, A., Trotta, M.P., Murri, R., Castelli, F., Narciso, P., Noto, P., Vecchiet, J., Monforte, A., Wu, A. & Antinori, A. 2002.

Correlates and predictors of adherence to highly active antiretroviral therapy: overview of published literature. *Journal of Acquired Immune Deficiency Syndromes*, 31: S123-S127.

Anderson, J. M., Wiggins, S., Rajwani, R., Holbrook, A. Blue, C. and Ng, M. 1995.

Living with a chronic Illness: Chinese-Canadiana and Euro-Canadian women with diabetes: exploring factors that influence management. *Social Science and Medicine*, 41: 181-195.

Anderson, K.W. 1998.

Utility of the five-factor model of personality in psychotherapy aptitude-treatment interaction research. *Psychotherapy Research*, 8: 54-70.

Ankrah, E.M. 1993.

The impact of HIV and AIDS on the family and other significant relationships: the African clan revisited. *AIDS Care,* 5: 5-22, cited in Forehand *et al*., 1999.

Araujo, G. Arsdel, P. & Holmes, T. 1973.

Life change, coping ability and chronic intrinsic asthma. *J Psychosom Res,* 17: 359-363.

Arntz, T. 2002.

Social support mechanism available to households in Welkom and Qwa-Qwa. Unpublished M-dissertation: University of Free State.

Ashforth, A. 2005.

Witchcraft, violence, and democracy in South Africa. Chicago, IL: University of Chicago Press.

Astin, J.A. 1998

Why patients use alternative medicine: results of a national survey. *Journal of American Medical Association,* 279(19): 1548-1553.

Babbie, E. & Mouton, J. 2001

The practise of social research. Cape Town: Oxford University Press, South Africa.

Baer, H.A, Singer, M., Susser, I. 1997.

Medical Anthropology and the world system: a critical perspective. Bergin & Garvey: Westport.

Barnett, T. 2004.

HIV: A Challenge for Anthropology. *Anthropology Today,* 20(4): 1–2.

Bartlett, J.A. 2002.

Adressing the challenges of adherence. *Journal of Acquired Immune Deficiency Syndrome,* 29: S2-S10.

Becker, M.H. 1985.

Patient adherence to prescribed therapies. *Medical Care,* 23(5): 539-555.

Beckfield, J. 2004.

Does income inequality harm health? New cross-national evidence. *Journal of Health and Social Behaviour,* 45: 231-248.

Berger, P. & Luckmann, T. 1966.

The social construction of reality: a treatise in the sociology of knowledge. Garden City, New York: Doubleday

Bernard, H.R. 1995.

Research Methods in Anthropology: qualitative and quantitative approaches 2nd ed. Walnut Creek, California, USA: Altamira Press.

Bernstein, A.J. & Van Rooyen, C.A.J. 1994.

Socio-cultural factors and their importance in working with people with AIDS in South Africa. *Social Work*, 30(4): 375-381.

Bharat, S. 1995.

HIV and AIDS and the family: issues in care and support. *The Indian Journal of Social Work*, LVI, 177-193.

Bhui, K, & Bhugra, D. 2002.

Explanatory model for mental distress: implication for clinical practice and research. *British Journal of Psychiatry,* 181: 6-7.

Binagwaho, A. & Ratnayake, N. 2009.

The role of social capital in successful adherence to antiretroviral therapy in Africa. *PLoS Medicine,* 6(1): 10-11.

Booysen, F. & Matebesi, Z. 2003.

The socio-economic impact of HIV/AIDS on households: pilot study in Thabong/Welkom and Qwaqwa. A congress on the economic impacts of HIV and AIDS and its impact on governance. *Kievits Kroon Country Estate*, Pretoria, 05 March.

Booysen, F. LE R. 2005.

Correlates of self-reported adherence to anti-retroviral treatment: Evidence from the public sector ART programme in the Free State province. Paper presented at the Unity and Accountability, 2nd South African AIDS Conference, Durban, South Africa.

Borofsky, R., Barth, F., Shweder, R.A., Rodseth, L. & Stolzenberg, N.M. 2001.

When: a conversation about culture. *American Anthropologist*, 103(2): 432-446.

Bor, R., Miller, R. & Goldman, E. 1993.

HIV and AIDS and the family: a review of research in the first decade. *Journal of Family Therapy*, 15(2): 187-204.

Boulle, A., Bock, P. Osler, M., Cohen, K., Channing, L., Hilderbrand, K., Zweigenthal, V., Slingers, V.N., Cloete, K. & Abdullah, F. 2005.

Antiretroviral therapy and early mortality in South Africa*, Bulletin of the World Health Organisation*, September 2008.

Burgoyne, R.W. 2005.

Exploring direction of causation between social support and clinical outcome for HIV-positive adults in the context of Highly active antiretroviral therapy. *AIDS CARE*, 17(1): 111-124.

Bury, M. 2001.

Illness narratives: Fact or fiction? *Sociology of Health and Illness*, 23(3): 263-285.

Callan, A. & Littlewood, R. 1998.

Patient satisfaction: ethnic origin or explanatory model? *Internal Journal of Social Psychiatry,* 44(1): 1-11.

Catz, S.L., Kelly, J.A., Bogart, L.M. Benotsch, E.G. & McAuliffe, T.L. 2000.
Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychology*, 19(2): 124-133.

Carrieri, M.P., Raffi, F., Lewden, C., Sobel, A., Michelet, C., Cailleton, V., Chene, G., Leport, C., Moatti, J, Spire, B & APROCO study group. 2003.
Impact of early versus late adherence to highly active antiretroviral therapy on immune-virologic response: a 3 year follow-up study. *Antiviral Therapy,* 8: 585-594.

Carillo, J.E., Green, A.R. & Betancourt, J.R. 1999.
Cross-Cultural Primary Care. *Annals of Internal Medicine,* 130(10): 829-834.

Carballo, E., Cadarso-Sua´ rez, C., Carrera, I., Fraga, J., de la Fuente, J. Ocampo, A., Ojea, R., & Prieto, A. 2004.
Assessing relationships between health-related quality of life and adherence to antiretroviral therapy. *Quality of Life Research*, 13: 587-599.

Chandra, P., Deepthivarma, S. & Manjula, V. 2003.
Disclosure of HIV infection in South India: patterns, reasons and reactions. *AIDS Care,* 15: 207-215.

Chesney, M.A. 2000a.
Factors affecting adherence to antiretroviral therapy. *Clinical Infection Diseases,* 30: S171-176.

Chesney, M.A., Morin, M. & Sherr, L. 2000b.
Adherence to HIV combination therapy. *Social Science & Medicine*, 50: 1599-1605.

Christensen, A.J. 2000.

Patient-by-treatment context interaction in chronic disease: a conceptual framework for the study of patient adherence. *Psychosomatic Medicine*, 62: 435-443.

Christensen, A.J. & Johnson, J. 2002.

Patient adherence with medical regimens: an interactive approach. *American Psychological Society*, 11(3): 94-97.

Chrisman, N.J. & Johnson, T.M. 1996.

Clinically Applied Anthropology. In Sargent, C.F. & Johnson, T.M. (eds). Medical Anthropology: Contemporary Theory and Method. Praeger: Westport. Connecticut.

Cohen, M.Z., Tripp-Reimer,T., Smith, C., Sorofman, B. & Lively, S. 1994.

Explanatory Models of Diabetes: Patient Practitioner Variation. *Social Science and Medicine,* 38: 59-66.

Cole, S.R., Hernan, M.A., Robins, J.M., Chmiel, J. & Detels, R. 2003.

Effect of Highly Active Antiretroviral Therapy on time to Acquired Immunodeficiency Syndrome or death using marginal structural models. *American Journal of Epidemiology*, 158: 687-694.

Coleman, J.S. 1988.

Social capital in the creation of human capital. *American Journal of Sociology,* 94: S94-120.

Cockerham, W.C. 1995.

Medical Sociology. Engelwoodcliff, New Jersey: Prentice Hall.

Conrad, P. 1985.

The meaning of medications: another look at compliance*. Social Science and Medicine,* 20 (1): 29-37.

Coetzee, D., Hildebrand, K., Boulle A., Maartens, G., Louis, F., Labatala, V., Reuter, H., Ntwana, N. & Goemaere, E., 2004.

Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa. *AIDS*, 18(6): 887-895.

Daly, J. McDonald, I. & Willis, E. 1992.

Researching Health Care: Designs, Dilemmas, Disciplines. Routledge: London and New York.

Dean, K. 1981.

Self-care response to illness: A selected review. *Social Science & Medicine,* 150: 673-687.

Dela Cruz, F.A., & Galang, C.B. 2007.

The illness, beliefs and perceptions, and practice of Filipino Americans with hypertension. *Journal of the American Academy of nurse Practitioner,* 20:118-127.

Declaration of the Alma-Ata, 1978.

International conference on primary health care, Alma-Alta, USSR, 6-12 September.

Denzin, N.K. 1989.

Interpretative Interactionism. Newbury Park, CA: Sage Publications.

Denzin, N.K. & Lincoln, Y.S. (eds.). 1994a.

Handbook of Qualitative Research. London: Sage Publications.

Denzin,N.K. & Lincoln, Y.S. 1994b.

Introduction: entering the field of qualitative research. In: Denzin, N.K. & Lincoln, Y.S. (eds) *Handbook of Qualitative Research*. Thousands Oaks, California, USA: Sage publication.

Department of Health 2003.

Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa, Pretoria: Department of Health.

De Reuck. C.J. 2008.

Adherence and sustained access to antiretroviral treatment in the Free State public health sector: a gender perspective. Unpublished Phd thesis. University of the Free State.

De Villiers, S. 1985.

Consideration of Illness causation among some Xhosa speaking people. *South African Journal of Ethnology*, 8(2): 48-52.

De Villiers, S. 1991.

Tuberculosis in anthropological perspective. *South African Journal of Ethnology,* 16(1): 69-72.

De Villiers, S. 1993

An anthropological investigation of some Xhosa-speaking patients' perceptions and behaviour in a hospital context. Unpublished Phd thesis. University of South Africa.

De Wet, T. 1998.

Doepa after Dark. Protective Medicines for Infants in Soweto in South Africa. Unplished Anthropology Dissertation.

Dimatteo, M.R. & Hays, R. 1982.

Social Support and Serious illness. Gottlied, B.J. (ed) *Social Networks and Social Suppor*t. Beverly Hills: Sage Publications.

Dimatteo, M.R., Giordani, O.J., Lepper, H.S. & Croghan, T.W. 2002.

Patient adherence and medical treatment outcomes. A meta-analysis. *Medical Care*, 40 (9): 794-811.

Donovan, J.L. & Blake, D.R. 1992.

Patient non-compliance: deviance or reasoned decision-making? *Social Science & Medicine, 34(5)*: 507-513.

Doyal, L. 2001.

Sex, gender and health: the need for a new approach. *British Medical Journal,* 323: 1061-1063.

Dressler, W.W. 1994.

Cross-Cultural Differences and Social Influences in Social Support and Cardiovascular Disease. New York: Plenum Publishing.

Dressler, W.W. 1996.

Culture, Stress and Disease. In: Sargent, C.F. & Johson, T.M. (eds). *Medical Anthropology-contemporary Theory and Methods*. Wesport, Connecticut: Praeger Publishers.

Durkheim, E. (1897) 1951.

Suicide. Glencoe, IL: Free Press.

Duran, S., Saves, M., Cailleton, V., Sobel, A. & Carrieri, M.P. 2001.

Failure to maintain long term adherence to highly active antiretroviral therapy: the role of lipodystrophy. *AIDS,* 15: 2441-2444.

Du Toit, B.M. 1998.

Modern Folk Medicine in South Africa. *South African Journal of Ethnology,* 21(4): 145-151.

Dyck, I. 1998.

Multicultural Society. Jones, D., Blair, S.E.E., Hartery, T. & Jones, K.R. Sociology and Occupational Therapy: An integrated approach. London: Churchhill Livingstone.

Edward, L. 2006.

Perceived social support and HIV and AIDS medication adherence among African American women. *Qualitative Health Research*, 16(5): 679-691.

Edward, J.M., Nachega, J.B., Buchan, I., Orbinski, J., Attaran, A., Singh, S., Rachlis, B., Wu, P., Cooper, C., Thabane, L., Wilson, K., Guyatt, G.H. & Bangsberg, D.R. 2006.

Adherence to antiretroviral therapy in Sub-Saharan Africa and North America: a meta-analysis, *Journal of American Medical Association,* 296(6): 679-690.

Eisenberg, L. 1977.

Disease and sickness: distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry,* 1: 9-23.

Eisenberg, D.V., Kessler, R.C., Foster, C., Calkins, D.R. & Delbanco, T.L. 1993.

Unconventional medicine in the United States: prevalence, costs, and patterns of use. *New England Journal of Medicine*, 328(4): 246-252.

Eisenberg, D.V., Davis, R.B., Ettner, S.L., Appel, S., Wilkey, S., Van Rompay, M. & Kessler, R.C. 1998.

Trends in alternative medicine use in the United States: 1990-1997 results of a follow-up national survey. *Journal of the American Medical Association*, 280: 1569-1575.

Ellen, I.G., Dillman, K. & Mijanovich T. 2001.

Neighborhood effects on health: exploring the links and assessing the evidence. *Journal of Urban Affairs* 23: 391–408.

Ember, C.R. & Ember, M. 2000.

Anthropology (4th ed.). London: Prentice-Hall.

Ember, C.R., Ember M. & Peregrine, P.N. 2005.

Anthropology (11th ed.). United States of America: Nancy Robersts.

Emerson, R.M., Fretz, R.I. & Shaw, L.L. 2001.

Participant Observation. In Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, l. (eds). *Handbook of Ethnography*. London: SAGE Publication.

Engel, G. 1977

The need for a new medical model: a challenge for biomedicine. *Science,* 196: 129-136.

Erstad, I. 2006

The resurgence of tuberculosis in South Africa: an investigation into the socio-economic aspects of the disease in a context of structural violence in Grahamstown, Eastern Cape. Unpublished MA: Rhodes University.

Evian, C. 2000.

Primary AIDS Care (3rd ed.). Houghton: Jacana Education.

Farmer, P. 1997.

Social Scientists and the new tuberculosis. *Social Science and Medicine,* 44(3): 347-358.

Ferraro, G. 2001.

Cultural Anthropology: An Applied Perspective (4th ed.). Belmont, CA, USA: Wadsworth/Thompson Learning.

Finkler, K. 1984.

The Non-sharing of Medical Knowledge Among Spiritualist Healers and Their Patients: A Contribution to the Study of Intra-cultural Diversity and Practitioner-Patient Relationship. *Medical Anthropology,* 8: 195-209.

Foster, G.M. 1976.

Disease etiologies in non-western medical systems. *American Anthropologists,* 78(4): 773-782.

Garro, L. C. 1986.

Intra-cultural variation in Folk Medical Knowledge: A comparison between curers and non-curers. *American Anthropologist,* 88: 351-370.

Gary, D. 1994.

Lay conceptions of autism: parents' explanatory models. *Medical Anthropology*, 16(2): 99-118.

Gatti, M.E., Jacobson, K.L., Gazmararian, J.A., Schmotzer, B. & Kripalani, S. 2009.

Relationship between beliefs about medications and adherence. *American Journal of Health-System Pharmacy*, 66(7): 657-664.

Geertz, C. 1973.

Thick Description: towards an interpretive theory of culture, in *The Interpretation of Culture*. New York: Basic Book. Pp. 3-30.

Gethin, G. 2002.

Patient compliance and chronic wounds. *Nurs Times,* 98(14): 60-62.

Gifford, A.L., Bormann, J.E., Shively, M.J., Wright, B.C., Richman, D.D., & Bozette, S.A. 2000.

Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. *Journal of Acquired Immune Deficiency Syndromes*, 23(5): 386-395.

Goffman, E. 1969.

The Presentation of Self in Everyday Life. Penguin: London.

Gordin, G., Cote, J., Naccachie, H., Lambert, L.D. & Trotteir, S. 2005.

Prediction of adherence to antiretroviral therapy: a one year longitudinal study. *AIDS Care*, 17(4): 493-504.

Gottlieb, B.H. 1981.

Social Networks and Social Support in Community Health Care*. Gottlied, B.H. (ed) Social network and Social Support*. Beverly Hills: Sage Publications.

Greeff, M., Phetlhu, R., Makoae, L.N., Dlamini, P.S., Holzemer, W.L., Naidoo, J.R., Kohi , T.W., Uys, L.R. & Chirwa, M.L. 2008.

Disclosure of HIV status: experiences and perceptions of persons living with HIV and AIDS and nurses involved in their care in Africa. *Qualitative Health Research,* 18(3): 311-324.

Green, E. 1999.

Indigenous Theories of Contagious Disease. Walnut Creek, CA: Alta-Mira Press.

Hagerdorn, R. & Sanford, L. 1971.

Introduction to Social Research. New York: McGraw-Hill.

Hallenbeck, J., Goldstein, M.K. & Mebane, E.W. 1996.

Cultural consideration of death and dying in the United States. *Clinics in Geriatrics,* 12(2): 393-406.

Hammond-Tooke, W.D. 1989.

Rituals and Medicines: indigenous healing in South Africa. Johannesburg: Ad Donker Publishers.

Hammond-Tooke, W.D. 1993

The Roots of Black South Africa. Johannesburg: Jonathan Ball Publishers.

Hammond-Tooke, W.D. 1998.

Selective borrowing? The possibility of San Shamanic Influence on Southern Bantu Divination and Healing practices. *South African Archaeological Bulletin,* 53: 9-15.

Hahn, R. 1995.

Sickness and Healing: an Anthropological Perspective. New Haven: Yale University Press.

Hardon, A., Boonmongkon, P., Streefland, P., Tam, M.L., Hongivatan, T.; Van der Geest, S., Van Staa, A & Varkevisser, C. 1995.

Applied health research manual- anthropology of health and health care. Amsterdam: University of Amsterdam.

Harpham, T., Grant, E. & Thoma, E. 2002.

Measuring social capital within health surveys: key issues. *Health Policy and Planning*, 17(1): 106-111.

Al-Hassan, M.A. & Omran, S.M. 2005.

The effects of health beliefs on health care-seeking behaviour decisions of Jordanian patients with myocardial infarction symptoms. *International Journal of Nursing Practice*, 11:13-20.

Hastrup, K. & Hervik, P. 1994.

Introduction. In Hastrup, K. & Hervik, P. (eds). *Social Experience and Anthropological Knowledge*. Routledge: London. p. 1-12.

Haviland, W.A. 1990.

Cultural Anthropology (6th ed.). Fort Worth, Tex, Holt, Rinehart & Winston.

Haviland, W.A. 2000.

Cultural Anthropology (9th ed.). Fort Worth: Harcourt Brace College Publishers.

Hawkins, C. & Murphy, R. 2007.

Adherence to antiretroviral therapy in resource-limited settings: everything matters. *AIDS*, 21(8): 1041-1042.

Hays, B.R., McKusick, L. Pollack, L. Hillard, R. Hoff, C. & Coates, T.J. 1993.

Disclosing HIV seropositivity to significant others. *AIDS Care,* 7: 415-431.

Heckman, T.G., Somlai, A.M., Kalichman, S.C., Franzoi, S.L. & Kelly, J.A. 1998.
Psychological difference between urban and rural people living HIV and AIDS. *Journal of Rural Health*, 14(2): 138-145.

Heggenhougen, H.K. 2000.
More than just 'interesting!' Anthropology, health and human rights. *Social Science and Medicine*, 50: 1171-1175.

Helman, C. 1996.
Culture, Health and Illness*:* an introduction for health professionals (3rd ed.). Oxford: Butterworth-Heinemann.

Helman, C. 2000.
Culture, Health and Illness (4th ed.). Oxford Boston: Butterworth-Heinemann.

Herselman, S. 1996.
Some problems in health communication in a multicultural clinical setting: A South African experience. *Health Communication*, 8(2): 153-170.

Herselman, S. 2007.
Health Care through a cultural lens: Insights from Medical Anthropology. *Current Allergy & Clinical Immunology,* 20 (2): 62-65.

Ho, M. 2004.
Socio-cultural aspects of tuberculosis: a literature review and a case study of immigrant tuberculosis. *Social Science & Medicine,* 59: 753-762.

Hodgson, I. 2000.
Culture, meaning and perceptions: explanatory models and the delivery of HIV care. 13th International AIDS conference, Durban, South Africa, July 14th -19th.

Holt, R., Court, P., Vedhara, K., Homes, J. & Snow, M.H. 1998.
The role of disclosure in coping with HIV infection. *AIDS Care,* 10: 49-60.

Holzemer, W. & Uys, L. 2004.

Managing AIDS stigma. *Journal of Social Aspect of HIV and AIDS*, 1(3): 165-174.

Horne, R. 1999.

Patients' beliefs about treatment: the hidden determinant of treatment outcome. *Journal of Psychosomatic Research*, 47(6): 491-495.

Horne, R., Weinman, J. & Hanskins, M. 1999.

The beliefs about medicines questionnaire: a new method for assessing cognitive representation of medication. *Psychol Health*, 14 1): 1-29.

Hunt, L.M. & Arar, N.H. 2001.

An analytic framework for contrasting patient and provider views of the process of chronic disease management. *Medical Anthropology Quarterly*, 15(3): 347-367.

Huysamen, G.K. 1998.

Introductory Statistics and Research Design for the Behavioural Sciences. Cape Town: H & R Academica.

Ingstad, B. 1990.

The cultural construction of AIDS and its consequences in Botswana. *Medical Anthropology Quarterly,* 4 (1): 28-40.

Israelski, M. D., Gore-Felton, C, Power, R, Wood, M.J. & Koopman, C. 2001.

Socio-demographic characteristics associated with medical appointment adherence among HIVseropositive patients seeking treatment in a county outpatient facility. *Preventive Medicine*; 33: 470–475.

Jaco, E.G. 1958.

Introductory: Medicine and Behavioural Science. In Jaco (ed.) *Patients, Physicians and Illness*, E.G. Glencoe: Free Press.

Janz, N.K. & Becker, M.H. 1984.
The Health Belief Model: A decade later. Health Sduc. Q: Spring.

Janzen, M.J. 1987.
Therapy management: Concepts, Realty, Process. *Medical Anthropology Quarterly,* 1(1): 68-84.

Janzen, M.J. 1978.
The Quest for Therapy in Lower Zaire. Berkeley: University of California Press.

Jiang H., Deeks, S.G., Kuritzkes, D.R., Lallemant, M., Albrecht, M. & De Gruttola, V. 2003.
Assessing Resistance Costs of Antiretroviral Therapies via Measures of Future Drug Options. *Journal of Infectious Diseases,* 188: 1000-1008.

Joint Health and Treasury Task Team 2003.
Summary report of the Joint Health and Treasury Task Team charged with examining treatment options to supplement comprehensive care for HIV and AIDS in the public health sector. Pretoria: Joint Health and Treasury Task team.

Jones, D, Blair, S.E.E., Hartery, T. & Jones, R.K. 1988.
Sociology and Occupational Therapy. Edinburg: Churchhill Livingstone United Kingdom.

Kalichman, S.C., Ramachandran, B.A. & Catz, S. 1999a.
Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine,* 14: 267-273.

Kalichman, S.C., Ramachandran, B.A. & Catz, S. 1999b.
Barriers to HIV and AIDS treatment and treatment adherence among African American adults with disadvantaged education. *Journal of the Medical Association,* 19(8): 439-446.

Kissinger, P., Cohen, O., Brandon, W., Rice, J., Morse, A., Clark, R., 1995. Compliance with public sector HIV medical care. *Journal. National Medical Association,* 87(1): 19-24.

Kleinman, A, Eisenberg, M.D. & Good, B. 1978. Culture, illness and care. Clinical lessons from anthropologic and cross-cultural research*. Annals of Internal Medicine,* 88: 251-258.

Kleinman, A, Eisenberg, M.D. & Good, B. 2006 reprint. Culture, illness and care. Clinical lessons from anthropologic and cross-cultural research. The Journal of Lifelong Learning in Psychiatry, 4(1):140-149.

Kleinman, A., Das, V. & Lock, M. 1997. Introduction. In Kleinman, A., Das, V. & Lock, M. (eds). Social Suffering. University of California Press: Berkeley. p. ix-xxvii.

Kleinman, A. 1980. Patients and Healers in the Context of Culture: an exploration of the borderline between anthropology, medicine and psychiatry. Berkeley: University of California Press.

Kleinman, A. 1987. Anthropology and Psychiatry.The role of culture in cross-cultural research on illness. *British Journal of Psychiatry,* 151: 447-454.

Kleinman, A. 1988. The Illness Narratives: Suffering, Healing and the Human Condition. Basic Book Inc: United States of America.

Kleinman, A. 1995. Writing at the margin. Discourse between Anthropology and Medicine. Berkeley: University of California Press.

Körner, H. 2007.

Negotiating Cultures: Disclosure of HIV-Positive status among people from minority ethnic communities in Sydney. *Culture, Health & Sexuality*, 9(2): 137-152.

Kriel, J.D. 1997.

The North Sotho World View and Disease Concepts. Department of Anthropology and Archaeology. University of Pretoria.

Kriel, J.D. & Mapogole, Molebatsi M. 1998.

To be clogged-up by an impure woman: a male malady among the North Sotho. *South African Journal of Ethnology*, 21(4): 181-184.

Kroeber, A. & Kluckhohn, C. 1952.

Culture. A Critical Review of Concepts and Definitions. Papers of the Pedagogy Museum, Harvard University, 47.

Lassiter, J.E. 1999.

African Culture and Personality: Bad Social Science, effective Social Activism, or a Call to reinvent Ethnology? 3(2):1. Online URL:http://web.africa.ufl.edu/asq/v3/v3i2a1.htm 08/09/2009.

LeCompte, M.D. & Schensuls, J.J. 1999.

Designing and Conducting Ethnographic Research. London: Altamira Press.

Lerner, B.H. 1997.

From careless consumptives to recalcitrant patients; the historical construction of non-adherence. *Social Science and Medicine,* 45(9): 1423-1431.

Liburd, L. Namageyo-Funa, A., Jack, L. & Gregg, E. 2004.

Views from within and beyond: illness narratives of African-American men with type 2 diabetes. *Diabetes Spectrum,* 17(4): 219-224.

Lieban, R.W. 1973.

“Medical Anthropology. In Honigman, J.J. (ed.) *Handbook of Social and Cultural Anthropology*. Chicago: Rand Morally.

Liddell, C., Barrett, L. & Bydawell, M. 2005.

Indigenous representation of illness and AIDS in Sub-Saharan Africa. *Social Science and Medicine,* 60: 691-700.

Li, J. 2008.

Ethical challenges in participant observation: a reflection on ethnographic fieldwork. *The Qualitative Report*, 13(1): 100-115.

Li Li, Wu. S., Wu, Z., Sun, S., Cui, H. & Jia, M. 2006.

Uniderstanding family support for people living with HIV and AIDS in Yunnan, China. *AIDS and Behaviour*, 10(5): 509-517.

Littlewood, R. 1990.

From categories to context: A Decade of the New Cross-Cultural Psychiatry. *British Journal of Psychiatry,* 156: 308-327.

Lock, M. & Nichter, M. 2002.

Introduction. From documenting medical pluralism to critical interpretations of globalized health knowledge, policies, and practices. In Nichter, M. & Lock, M. (eds). *New Horizons in Medical Anthropology*. Essays in honour of Charles Leslie. Routledge: London. p. 1-34.

Lomas, T. 1998.

Social capital and health: implication for public health and epidemiology. *Social Science and Medicine*, 47(9): 1181-1188.

Lynch, J. 2000.

Income Inequality and Health: Expanding the Debate. *Social Science& Medicine,* 51(7): 1001-5.

Lynch,J., Smith, G.D., Harper, S., Hillemeier, M., Ross, N. Kaplan, G.A. & Wolfson, M. 2004.

Is income inequality a determinant of population health? Part 1: a systematic review. *The Milbank Quarterly*, 82(1): 5-99.

Lynch, J. and Smith, G.D. 2003.

Rates and States: Reflections on the Health of Nations. *International Journal of Epidemiology,* 32 (4): 663- 70.

Luszczynska, A., Sarkar, Y. & Knoll, N. 2007.

Received social support, self-efficacy, and finding benefits in disease as predictors of physical functioning and adherence to antiretroviral therapy. *Patient Education and Counselling*, 66: 37-42.

Mabunda, M.M. 2001.

Perceptions of diseases, illness and healing among selected black communities in the Northern Province, South Africa. *South African Journal of Ethnology,* 24(1): 11-16.

Malcolm, S.E., Rosen, R.K. & Stone, V.E. 2003.

An examination of HIV/AIDS patients who have excellent adherence to HAART. *AIDS Care,* 15 (2): 251-261.

Mannheimer, S.B., Matts, J., Telzak, E., Chesney, M., Child, C., Wu, A.W. & Friedland, G. 2005.

Quality of life in HIV-infected individuals receiving antiretroviral therapy is related to adherence. *AIDS CARE*, 17(1): 10-22.

Mannheimer, S., Friedland, G., Matts, J., Child, C. & Chesney, M. 2002.

The consistency of adherence to antiretroviral therapy predicts biologic outcomes for human immunodeficiency virus-infected persons in clinical trials*. Clinical Infectious Diseases*, 34: 1115-1121.

Marvel, M.K. 1993.

Involvement with psychosocial concerns of patients: Observations of practicing family physicians on a University Faculty. *Archives of Family Medicine,* 2:629-633.

Mbiti, J.S. 1969.

African Religion and Philosophy. Oxford: Heinemann International.

McElroy, A. 1990.

Biocultural models in studies of human health and adaptation. *Medical Anthropology Quarterly,* 4 (3): 243-265.

McElroy, A. 1996.

Medical Anthropology. *Encyclopedia of Cultural Anthropology*. New York: Henry Holt.

McElroy, A., & Townsend, P.K. 1985.

Medical Anthropology in Ecological Perspective. Boulder, Colo.: Westview Press.

Mehta, S., Moore, R.D., Graham, N.M.H., 1997.

Potential factors affecting adherence with HIV therapy. *AIDS,* 11: 1665-1670.

Metcalf, P. 2002.

They lie, we lie. Getting on with anthropology. Routledge: London.

Moerman, D.E. 1979

Anthropology of Symbolic Healing. *Current Anthropology,* 20 (1): 59-80.

Mohanna, P. & Kamath, A. 2009.

Family support for reducing morbidity and mortality in people with HIV and AIDS (review). *The Cochrane Library*, 4: 1-12.

Mugyenyi, P. 2005.

ART roll-out: the Ugandan Experience. ARV international conference. Bloemfontein, South Africa 30th March-1st April.

Murdock, G. P. 1980.

Theories of Illness: A World Survey. Pittsburgh.

Murphy, D.A., Roberts, K.J. Hoffman, D. Molina, A. 2003.

Barriers and successful strategies to antiretroviral adherence among HIV-infected monolingual Spanish-speaking patients. *AIDS Care,* 15(2): 217-230.

Murphy, D.A., Marelich, W.D., Hoffman, D., & Steers, W.N. 2004.

Predictors of antiretroviral adherence. *AIDS CARE*, 16(4): 417-484.

Muula, R., Ngulube, T.J., Siziya, S., Makupe, C.M., Umar, E., Prozesky, H.W., Wiysonge, C.S., & Mataya, R.H. 2007.

Gender distribution of adults patients on highly active antiretroviral therapy (HAART) in Southern Africa: a systematic review. *BMC Public Health*, 7(63): 1-8.

Myoung Ok Cho, R.N. 2004.

Health care seeking behaviour of Korean women with lymphedema. *Nursing and Health Sciences*, 6: 149-159.

Nanda, S. & Warms, 2002.

Cultural Anthropology. Belmont: Wadsworth Publishing Co.

Neuman, W.L. 2000.

Social research methods: qualitative and quantitative approaches. Boston: Allyn & Bacon.

Ngubane, H.1977.

Body and Mind in Zulu Medicine: an ethnography of health and disease in Nyuswa-Zulu thought and practice. London: Academic Press.

Ohmit, S., Schuman, P., Schoenbaum, E., Rompalo, A., Cohen, M., Richardson, J., Sacks, H., Young, M., 1998.

Adherence to antiretroviral therapy (ART) among women in the HIV Epidemiology Research Study (HERS) and Women's Inter-Agency HIV Study (WIHS). In: Abstract 32347, 12th World AIDS Conference Geneva, 28 June-3 July.

Okello, E. & Ekblad, S. 2006.

Lay concepts of depression among the Baganda of Uganda. *Transcultural Psychiatry,* 43 (2): 287-313.

Orrell, C., Bekker, L.G. & Wood, R. 2001.

Adherence to antiretroviral therapy- achievable in South Africa context? *South African Medical Journal, 91(6): 483-484.*

Orrell, C., Bangsberg, D.R., Badri, M. & Wood, R. 2003.

Adherence is not a barrier to successful antiretroviral therapy in South Africa. *AIDS,* 17(19): 1369-1375.

Orrell, C. 2005.

Antiretroviral adherence in a resource-poor setting. *Curr HIV/AIDS Rep*., 2(4): 171-176.

Osterberg, M.D. & Blaschke, M.D. 2005.

Adherence to medication. *The New England Journal of Medicine,* 353(5): 487-497.

Oyugi, J.H., Byakika-Tusiime, J., Ragland, K., Laeyendecker, O., Mugerwa, R., Kityo, C., et al. 2007.

Treatment interruptions predict resistance in HIV-positive individuals purchasing fixed-dose combination generic HIV antiretroviral therapy in Kampala, Uganda. *AIDS*, 21(8): 965-971.

Park, E.L., Betacourt, J.R., Miller, E., Nathan, M., MacDonald, E., Ananeh-Firempong, O. & Stone, V.E. 2006.

Internal medicine resident's perceptions of cross-cultural training. *Journal of General Internal Medicine, 21(5)*: 476-480.

Parker, R. & Aggleton, P. 2003.

HIV and AIDS related stigma and discrimination: a conceptual framework and implication for action. *Social Science and Medicine,* 57: 13-24.

Parker, R. 2001

Sexuality, Culture and Power in HIV and AIDS Research. *Annual Review of Anthropology,* 30: 163–179.

Parson, T. 1951.

The Social System. Glencoe, IL: The Free Press.

Pelser, A.J., Ngwena, C.G. & Summerton, J.V. 2004.

The HIV and AIDS in South Africa: trends, impacts and policy responses. In Van Rensburg, H.C.J. (ed.). *Health and Health Care in South Africa*. Pretoria: Van Schaik.

Petrak, J.A., Doyle, A.M., Smith, A., Skinner, C. & Hedges, B. 2001.

Factors associated with self disclosure of HIV serostatus to significant others. *British Journal of Health Psychology* 6, 69-79.

Pelto, P.J. & Pelto, G.H. 1997.

Studying knowledge, culture, and behaviour in applied medical anthropology. *Medical Anthropology Quarterly*, New Series, 11(2): 147-163.

Pequegnant, W., Bauman, L.J., Bray, J.H., Diclemente, R., Di-iorio, C., Hoppe, S.K., Jemmont, L.S., Krauss, B., Miles, M., Paikoff, R., Rapkin, B., Rotheram-Borus, M.J. & Szapocznik, J. 2001.

Measurement of the role of families in prevention and adaptation to HIV and AIDS. *AIDS and Behaviour*, 5(1):1-19.

Plowden, K. 2003.

A theoretical approach to understanding Black men's health-seeking behaviour. *Journal of Theory Construction and Testing, 7(1): 27-31.*

Phatak, H.M. 2006.

Relationship between beliefs about medications and non-adherence to prescribed chronic medications. *The Annals of Pharmacotherapy*, 40(10): 1737-1742.

Pretorius, E. 2004.

Complementary/Alternative and Traditional Health Care South Africa: In Van Rensburg, H.C.J. (ed.). *Health and Health Care in South Africa*. Pretoria: Van Schaik.

Powell-Cope, G.M., White, J., Henkelman, E.J. & Turner, B.J. 2003.

Qualitative and quantitative assessments of HAART adherence of substance-abusing women. *AIDS-Care,* 15(2): 239-249.

Power, R. 1998.

The role of qualitative research in HIV and AIDS. *AIDS,* 12: 687-695.

Redelinghuys, N. & Van Rensburg H.C.J. 2004.

Health morbidity and mortality: the health status of South African population. In Van Rensburg, H.C.J. (ed.). *Health and Health Care in South Africa*. Pretoria: Van Schaik.

Reynolds, N.R., Testa, M.A., Marc, L.G., Chesney, M.A., Neidig, J.L., Smith, S.R., Vella, S. & Robbins, G.K. 2004.

Factors Influencing Medication Adherence Beliefs and Self-Efficacy in Person Naïve to Antiretroviral Therapy: A multicentre, cross-sectional study. *AIDS and Behaviour, 8(2): 141-150.*

Rintamaki, L.S., Davis, T.C., Skripkauskas, S. Bennet, C.L. & Wolf, M.S. 2006.

Social Stigma Concerns and HIV Medication Adherence. *AIDS Patient and STDs,* 20(5): 359-368.

Risberg, G., Hamberg, K., & Johansson, E.E. 2006.

Gender perspective in medicine: a vital part of medical scientific rationality. A useful model for comprehending structures and hierarchies within medical science. *BMC Medicine*, 4(20): 1-5.

Roberts, K.J. 2000.

Barriers and Facilitators of HIV-Positive Patients' Adherence to Antiretroviral Treatment. *AIDS Patients Care and STDs,* 14(3): 155-168.

Rosenstock, I.M. 1990.

The Health Belief Model: explaining health behaviour through expectancies. In: Glanz K, Lewis FM, Reiner B.K. (eds.). *Health Behaviour and Health Education*. San Franciso: Josey-Bass.

Rosen, G. 1963.

The Evolution of Social Medicine. In the handbook of *Medical Sociology*, H.E. Freeman, S. Levine & L.G. Reeder (eds.). Englewood Cliffs: Prentice Hall.

Rosner, F.R. 2005.

Patient non-compliance: causes and solutions. *The Mount Sinai Journal of Medicine,* 73 (2): 553-559.

Runyan, W.A. 1982.

Life Histories and Psychobiography: explorations in theory and method. New York: Oxford University Press.

Russel, S. 2004.

The economic burden of illness for household in developing countries: A review of studies focusing on Malaria, Tuberculosis and Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome. *The American Journal of Tropical Medicine and Hygiene*, 71(1): 147-155.

Sargent, C.F. & Johnson, T.M. (eds.) 1996.

Introduction. In Sargent, C.F. & Johnson, T.M. (eds.). *Medical Anthropology:* contemporary theory and methods. Revised Edition. Westport, Connecticut: Praeger Publishers.

Scheper-Hughes, N. & Lock, M. 1987.

The mindful body: a prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly*, 1(1): 6-41.

Schilder, A.J., Kennedy, C., & Goldstone, I.L. 2001.

Been dealt with as a whole person. Care seeking adherence. The benefits of culturally competent care. *Social Science and Medicine,* 52 (11): 1643-1659.

Sethosa, E. & Peltzer, K. 2005.

Evaluation of HIV counselling and testing, self-disclosure, social support and sexual behaviour change among a rural sample of HIV reactive patients in South Africa. *Curationis*, 28(1): 29-41.

Seymour-Smith, C. 1990.

Macmillan Dictionary of Anthropology. London: Macmillan Press.

Schultz, A.E. & Lavenda, R.H. 1990.

Cultural Anthropology: a perspective on human condition (2nd ed.). St Paul, MN, USA: West Publishing Company.

Sharma, P. & Garg, S. 2006.

Operationalizing gender in context of HIV and AIDS. *Indian Journal of Community Medicine*, 31(3): 117-119.

Sibbald, B., White, P. & Pharoah, C. 1988.

Relationship between psychological factors and asthma morbidity. *Fam Pract,* 5: 12-17.

Singer, M. 1990.

Reinventing medical anthropology: toward a critical realignment. *Social Science and Medicine*, 30(2): 179-187.

Snow, 1983.

Traditional health beliefs and practices among lower class black Americans. In Cross Cultural Medicine. *The Western Journal of Medicine, 138: 820-828.*

Songwathana, P. & Manderson, L. 1998.

Perception of HIV and AIDS and caring for people with terminal AIDS in southern Thailand. *AIDS Care,* 10 (2): 155-165.

Sontag, S. 1983.

Illness as Metaphor and AIDS and its Metaphors. London: Penguin.

South African National Department of Health 2003.

Operational Plan for Comprehensive HIV and AIDS care, Management and Treatment for South Africa. Pretoria: National Department of Health.

Sowell, R.L., Lowenstein, A., Demi, A, Mizuno, Y. & Seals, B.F. 1997.

Resources, stigma, and patterns of disclosure in rural women with HIV infection. *Public Health Nursing*, 14(5): 302-312.

Spradley, J.P. 1980.

Participant Observation. New York: Holt Rinehart and Winston.

Steen, T. & Mazonde, G. 1999.

Ngaka ya Setswana, ngaka ya sekgoa or both? Health seeking behaviour in Batswana with pulmonary tuberculosis. *Social Science & Medicine,* 48: 163-172.

Stone, V.E. 2001.

Strategies for optimizing adherence to highly active antiretroviral therapy: lesson learned from research and clinical practice. *Clinical Infection Diseases*, 33:865-872.

Stone, V.E., Hogan, J.W., Schuman, P., Rompalo, A.M., Korkontzelou, C., & Smith D.K. 2001.

Antiretroviral regimen, self-reported adherence and HIV patients' understanding of their regimen: survey of women in HER study. *Journal of Acquired Immune Deficiency Syndrome*, 28(2): 124-131.

Thagard, P. 1998.

Explaining disease: correlations, causes, and mechanisms. *Minds and Machines,* 8: 61-78.

The World Health Organisation Strategy, 2003.

Treating 3 million by 2005: making it happen. Geneva:UNAIDS.

Thomas, F. 2008.

Indigenous narratives of HIV and AIDS: Morality and blame in a time of change. *Medical Anthropology,* 27(3): 227-256.

Triandis, H., Bontempo, R., Villareal, M., Asai, M. & Lucca, N. 1988.

Individualism and collectivism: Cross-cultural perspectives on self-in-group relationships. *Journal of Personality and Social Psychology,* 54: 323-338.

Tresolini, C.P., Shugars, D.A. & Lee, L.S. 1995.

Teaching an integrated approach to health care: lessons learned from five schools. *Academic Medicine*, 70: 665-670.

Tseng, W. & Streltzer, J. 2008.

Cultural Competence in Health Care: A guide for professionals. Springer Science and Business Media: New York.

Turner, B.J., 2002.

Adherence to antiretroviral therapy by Human Immunodefiency Virus-infected patients. *Journal of Infectious Disease,* 185 (Suppl. 2): S143-S153.

UNAIDS Joint United Nations Programme on HIV and AIDS 2004.

Report on the Global HIV and AIDS Epidemic. Geneva: UNAIDS.

Van Rensburg. H.C.J. (ed.). 2004.

Health and health care in South Africa. Van Schaik Publishers: Pretoria.

Van Willigen, J. 1986.

Applied Anthropology: an introduction. Bergin & Garvey, South Hadley, Mass.

Vecchiato, N.L. 1997.

Sociocultural Aspects of Tuberculosis Care in Ethiopia. *Medical Anthropology Quarterly*, 11(2): 183-201.

Volmick, J. & Garder, P. 1997.

Systematic review of randomised controlled trials of strategies to promote adherence to tuberculosis treatment. *BMJ,* 315: 1403-1406.

Wagner, G.J. 2002.

Predictors of antiretroviral adherence as measured by self-report, electronic monitoring and medication diaries. *AIDS Patient Care and Sexually Transmitted Diseases*, 16(12):599-608.

Wamala, S., Merlo, J. Bostrom, G. Hogstedt, G. and Agren, G. 2007.
Socioeconomic disadvantage and primary non-adherence with medication in Sweden. *International Journal for Quality in Health Care*, 1-7.

Wax, R.H. 1979.
Gender and age in fieldwork and field work education: no good training is done by any man alone. Social Problems, 26: 509-523.

Wens, J., Vermeire, E., Royen PV, Sabbe, B. & Denekens, J. 2005.
GPs' perspectives of type 2 diabetes patients' adherence to treatment: A qualitative analysis of barriers and solutions**.** *BMC Fam Pract*, 6: 20. Published online. doi: 10.1186/1471-2296-6-20.

Weisner, S., Wolfe, W., Bangsberg, D., Thior, I., Gillbert, P., Makhema, J., Kebaabetswe, P., Dickenson, D., Mompati, K., Essex, M. & Marlink, R. 2003.
Barriers to antiretroviral adherence for patients living with HIV and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndrome*, 34(3): 281-288.

Wiebe, J.S. & Christensen, A.J. 1996.
Patient adherence in chronic illness: personality and coping in context. *Journal of Personality*, 64: 815-853.

Wilkinson, R.G. 2005.
The Impact of Inequality. How to make a sick society healthier. The New Press: New York.

Wikman, A., Marklund, S. & Alexanderson, K. 2005.
Illness, disease and sickness absence: an empirical test of differences between concepts of ill health. *J Epidemiol Community Health,* 59: 450-454.

World Health Organisation, 2003.

Diet, Nutrition and the Prevention of Chronic Disease. Report of a Joint WHO/FAO expert consultation. Geneva: UNAIDS.

World Bank 1997.

World Bank. Confronting AIDS: public priorities in a global epidemic. Oxford University Press: New York.

Wouters, E., Meulemans, H., van Rensburg, H.C.J., Heunis, J.C. & Mortelmans, D. 2007

Short-term physical and emotional health outcome of public ART in the Free State province of South Africa. *Qual Life Res,* 16: 1461-1471.

Wu, A.W. 2000.

Quality of life assessment comes of age in the era of highly active antiretroviral therapy*. AIDS,* 14: 1449-1451.

Yen, I.H. & Syme, S.L. 1999.

The social environment and health: A discussion of the epidemiologic literature. *Annual Review of Public Healt,* 20: 287-308.

Yin, R.K. 1994.

Case study research: design and methods (2nd ed.). London: Sage Publications.

Yin, R.K. 2003.

Case study research: designs and methods (3rd ed.). Thousands Oak California: Sage Publications.

Young, A. 1980.

An anthropological perspective on medical knowledge. *The Journal of Medicine and Philosophy,* 5(2): 102-116.

Zerwic, J.J., Sherry, D.C., Simmons, B. & Wung, S.F. 2003.
Noncompliance in heart transplantations: a role for the advanced practice nurse. *Prog Cardiovasc,* 18(3): 141-146.

Zumla, A. & Gandy, M. 2003.
Politics, science and the “new” tuberculosis. In Gandy, M. & Zumla, A. (eds). *The return of the white plague: global poverty and the “new” tuberculosis*. Versto: London.

SUMMARY

Although antiretroviral (ARV) medicines do not provide a cure for HIV and AIDS and are associated with other problems such as side effects and drug resistance, they can increase the length and quality of life, as well as the productivity of patients on antiretroviral therapy (ART). Antiretroviral regimens have improved survival rates and lowered the incidence of opportunistic infections in people with AIDS. Strict adherence to ART is crucial in order to maintain a low viral load and to prevent the development of drug resistant strains of the virus. However, some patients do not return for follow-up on schedule and the likely outcome for such patients is sub-optimal adherence to prescribed ARV regimens and possible treatment failure.

Anthropological studies have shown that patients' explanatory models are necessary additions to the treatment criteria used by health providers (Kleinman, 1980 & 1988; Nanda & Warms, 2002). Kleinman *et al.* (1978) introduced the concept of the explanatory model in applying anthropological insight to clinical practice. They maintain that, in the health care encounter, patients and practitioners may be working with different and competing models. If not properly managed, such divergent and incongruent models may result in ineffective treatment or non-compliance (*cf.* Jones *et al.*, 1998). If Eisenberg's (1977) assumption that, 'a patient suffers illnesses, and doctors diagnose and treat disease' is correct then Kleinman's (1980) pursuit to reconcile the social and medical constructs of ill health is a worthy endeavour. Unfortunately, such a comprehensive approach is for the most part, lacking in the literature. In line with Kleinman's view, this study argued that, HIV and AIDS, ARV medication adherence, prevention programmes and treatment readiness training cannot be studied and understood without taking into account the individual's explanatory

models (situated within and constrained by social context), as well as how individuals construct an understanding of and imposes meaning on the world around them.

Given the importance of proper adherence management, the aim of this study was to conduct an ethnographic inquiry into the nature and role of individuals' socio-cultural contexts in treatment adherence/non-adherence regardin antiretroviral treatment. In order to achieve this aim, three integrated ethnographic data collection methods, i.e., participant observation, in-depth interviews and focus group discussions were employed to better understand the socio-cultural context and experiential understanding of patients on ARV.

The results reinforced several important facts related to HIV and AIDS, ARV medication adherence, prevention programmes and treatment readiness training, and shed additional light on other areas of patient social interaction that might add value to current discourse/practices. The study concluded that patients' socio-cultural context provides crucial information that can be used not only to identify causal reasoning, understanding of ill health, treatment readiness training, prevention programmes and adherence to treatment, but to assist in ascertaining the most effective means of intervention within a particular society or community.

OPSOMMING

Alhoewel antiretrovirale (ARV) medikasie nie genesing vir VIGS bring nie en dit met ander probleme soos newe-effekte en middelweerstand geassosieer word, kan dit die lewensduur verleng van pasiënte wat antiretrovirale (ARV) terapie ontvang, asook hulle lewensgehalte en produktiwiteit verhoog. Antiretrovirale leefstyle het oorlewingsyfers verbeter en die voorkoms van opportunistiese infeksies in mense met VIGS verlaag. Streng nakoming van ART is noodsaaklik om ’n lae virale lading te handhaaf en die ontwikkeling van middelweerstandige stamme van die virus te voorkom. Sommige pasiënte keer egter nie vir geskeduleerde opvolgbesoeke terug nie en die waarskynlike uitkoms vir sodanige pasiënte is sub-optimale nakoming aan voorgeskrewe ARV-behandeling, asook moontlike mislukte behandeling.

Antropologiese studies toon dat pasiënte se verklarende modelle nodige aanvullings is tot die behandelingskriteria wat deur gesondheidsverskaffers gebruik word (Kleinman, 1980 & 1988; Nanda & Warms, 2002). Kleinman *et al.* (1978) het die konsep van die verklarende model bekendgestel deur antropologiese insigte in kliniese praktyk toe te pas. Hulle beweer dat pasiënte en praktisyns in die gesondheidsorg-ontmoeting met verskillende en kompeterende modelle kan werk. Indien dit nie behoorlik bestuur word nie, kan sulke uiteenlopende en inkongruente modelle ondoeltreffende behandeling of nie-nakoming tot gevolg hê (vgl. Jones *et al.*, 1998). Indien Eisenberg (1977) se veronderstelling dat ‘‘a patient suffers illnesses, and doctors diagnose and treat disease’’ waar is, is Kleinman (1980) se strewe om die sosiale en mediese konstrukte van siekte te versoen, ’n waardige onderneming. Ongelukkig word so ’n uitgebreide benadering grotendeels nie in die literatuur aangetref nie. In lyn met Kleinman se siening, is hierdie studie van mening dat MIV en VIGS, nakoming van ARV-medikasie, voorkomingsprogramme en behandelingsgereedheid-opleiding nie bestudeer en verstaan kan word sonder om die individu se verklarende modelle (binne-in en beperk deur sosiale konteks) in ag te neem nie, asook hoe individue begrip konstrueer en betekenis aan die wêreld rondom hulle heg.

Op grond van die belangrikheid van behoorlike nakomingsbestuur, is die doel van die studie om ’n etnografiese ondersoek te doen in die aard en rol van individue se sosio-kulturele kontekste in nakoming/nie-nakoming van behandeling ten opsigte van antiretrovirale behandeling. Om hierdie doel te bereik, is drie geïntegreerde etnografiese dataversamelingsmetodes, nl. deelnemende observasie, indiepte-onderhoude en fokusgroepbesprekings, gebruik om die sosio-kulturele konteks en ervaringsbegrip van pasiënte op ARV beter te verstaan.

Die resultate het verskeie belangrike feite wat verband hou met MIV en VIGS, nakoming van ARV-medikasie, voorkomingsprogramme en behandelingsgereedheid-opleiding versterk, en addisionele lig gewerp op ander areas van pasiënte se sosiale interaksie wat waarde tot huidige diskoers/praktyke kan toevoeg. Die studie het tot die gevolgtrekking gekom dat pasiënte se sosio-kulturele kontekste kritieke inligting verskaf wat gebruik kan word nie slegs om oorsaaklike redenering, begrip van swak gesondheid, behandelingsgereedheid-opleiding, voorkomingsprogramme en nakoming van behandeling te identifiseer nie, maar om ook te help om die doeltreffendste maniere van intervensie binne ’n spesifieke samelewing of gemeenskap te bepaal.

APPENDIX A
CONSENT FORM

SOCIO-CULTURAL CONTEXT OF PEOPLE ON HIV AND AIDS: AN ANTHROPOLOGICAL PERSPECTIVE

You are kindly invited to participate in this study. Before you agree to take part you need to understand what it involves.

Purpose of the survey

The aim of this study is to conduct an ethnographic inquiry into the nature and role of individuals' socio-cultural contexts on treatment adherence/non-adherence in respect of antiretroviral treatment.

What are the possible benefits in this survey?

The information that I will obtain from the study will help us improve our understanding of the ARV management with in a specific context.

What are the possible drawbacks or discomfort in participating in this survey?

None, however, I acknowledge that the talking about your experiences might be personal, emotional and sensitive to talk about.

Do I have to participate in this survey?

Your participation in this study is voluntary. Should you agree to participate, you are required to sign this form. You are free to withdraw from the study at any stage. Likewise, should you feel that further participation in this study would not be in your best interest, we will withdraw you from the study.

What will happen with the information?

By consenting to participate:

- I understand that the documentation will become the property of the University of the Free State;
- The information will be used for research and /or educational purposes.

Contact details

Should you have any questions concerning this study, please contact the following:

Name: Prof. P.A. Erasmus (study leader)	Phone number: 051-401 2363
Name: Mr. Joe Serekoane (researcher)	Phone number: 051-401 2651

I,…………………………………………………………(name of the participant) have read and understood all the information given to me about my participation in the survey and I have been given the opportunity to discuss it and ask questions. I voluntarily agree to take part in this survey. I also confirm that I have received a copy of this consent form.

____________________________ ____________________

Signature of informant Date

Interviewer, I have:

a	Determined the conditions/restrictions pertaining to the interview/interviewee		
	Anonymous	**Y**	**N**
	Other (Specify)		
b	Explained the nature and purpose of the survey to the participant	**Y**	**N**
c	Handed over a copy of the consent form	**Y**	**N**

APPENDIX B
INTERVIEW GUIDES

INTERVIEW GUIDE

Life history

- Tell me more about where you were born, your family, and some memorable events in your upbringing
- Tell me about your life right now (your work, your family etc.
- When were you diagnosed with HIV

Patient and Family Explanatory Models

- In what way did HIV affect your life?
- Your fears about having HIV
- What caused your HIV?

Symptoms Symbols

- What was going on in your body that led you to the realisation of ill health?
- What led to your diagnoses of HIV?
- At what point did you go to the western trained medical doctor?
- What other problems have you experienced because you have HIV?
- What kind of treatment (s) do you prefer for HIV?
- What role does home remedies or over the counter medication play in the management of your health?
- Do you have examples of such remedies?

Personal and interpersonal significance

- Describe what you did to manage your ill health?
- After the diagnosis with HIV, what did you do to manage it?
- Is there someone (or people) in your life who helps you to manage your HIV? If yes what are some of the things they would do?
- In what way have people in your life treated you differently after learning about your HIV status (if disclosed), or ill health (if not disclosed)?
- Of all the things the doctor/nurse or health care worker told you to do to manage your HIV, what are the most difficult recommendations for you to follow?
- Describe what makes these recommendations so hard to do consistently?
- In what way (s) has knowing that you have HIV affected the way your see yourself?
- Do you find that having HIV add to the stress in your life? if yes in what way (s)?

Culturally markers disorders

- What is your understanding of HIV?
- Have you told anybody outside the clinic about your HIV?
    - If yes how did they react to the news?
    - If no, what discourages you from telling?

Individual Questionnaire

General Information

1. Date of the interview:
2. Venue:
3. Language
4. Questionnaire number:

Section A: Biographical Data

1. Gender

Male		1
Female		2

2. Home language

Afrikaans		1
English		2
IsiXhosa		3
Sesotho		4
Setswana		5
Other	Specify	

3. Marital status

Single staying alone		1
Single staying with family (nuclear)		2
Single staying with family (extended)		3
Married staying with husband and children		4
Matri-focal (woman + woman staying together)		5
Other	specify	

4. Age category

18-21		1
22-25		2
26-29		3
30-33		4
24-37		5
38-41		6
42-46		7
47-50		8
50+		9

5. Educational qualification

5.1 What is the highest formal educational level that you have completed?

No formal education		0
Grade 1/Sub A		1
Grade 2/Sub B		2
Grade 3/Standard 1		3
Grade 4/STD 4/ABET L1		4
Grade 5/Standard 3		5
Grade 6/STD 4/ABET L2		6
Grade 7/Standard 5		7
Grade 8/STD 6/ABET L3		8
Grade 9/Standard 7		9
Grade 10/STD 8/ABET L4		10
Grade 11/Standard 9		11
Grade 12/STD 10/ABET L5		12
Diploma		13
Degree		14
Other	specify	

6. Employment status

I would like to find out more regarding your employment status

6.1 Are you working?

Yes		1
No		2

6.2 If you answered yes above (6.1), what type of job do you do?

Taxi driver		1
Truck driver		2
Skilled work	Specify	3
Unskilled work	Specify	4
Other	Specify	

6.3 If you answered no above (6.1), are looking for a job?

Yes		1
No		2

6.4 To what would you attribute your struggle to getting a job/employment?

HIV status		1
Lack of professional skills		2
Lack of education		3
Other	specify	

6.5 If you are employment what is your income per month?

R500-R1000		1
R1000-R2000		2
R2000-R4000		3
R4000 and above		4

6.6 If you answered no above (6.1), what is your main source (s) of income?

Government grant		1
Donation from NGO's		2
Parents	specify	3
Boyfriend/girlfriend salary		4
Husband/wife salary		5
Other	specify	

6.7 Does your monthly income enable you to cope with following medication regime?

6.7.1 Nutrition

Yes		1
No		2

6.7.1 Personal and environmental hygiene

Yes		1
No		2

6.7.2 Clothing

Yes		1
No		2

6.7.3 Medication

Yes		1
No		2

7. Religious Denomination

Roman Catholic Church		1
Dutch reformed Church		2
Apostolic Church of South Africa		3
Christian Revival Church		4
Apostolic Faith mission of South Africa		5
Other	specify	

Section B: Implementation of ARV treatment, patients experiences

1. Treatment duration

1.1 In which year of ARV treatment are you currently?

Less than a year		1
1st year		2
2nd year		3
3rd year		4
4th year and above		5

2. Treatment experience

I would like to find out about your experience of ARV treatment.

2.1 Did you receive information on ARV treatment at the time of your HIV+ diagnosis?

Yes		1
No		2

2.2 If you answered **yes** above, who informed you about ARV treatment?

Clinic		1
Radio		2
Department of Education		3
Department of Health		4
Friend	specify	5
Community organisation		6
Private doctor		7
Support group		8
Community volunteers		9
Home based carers		
Other	Specify	

2.3 Did you voluntary or involuntary disclose your HIV status to anybody?

Voluntary		1
Involuntary		2

2.3.1 If you answered **voluntary**, to whom did you make your HIV status known?

____

2.3.2 Why did you choose that specific person?

____

2.3.3 If you answered **involuntary**, who forced you to disclose your HIV status?

____

2.3.4 Why were you forced to disclose your HIV status?

____

3. Treatment Adherence

3.1 Do you often feel that your adherence (compliance) to treatment is in any way challenged?

Yes		1
No		2

3.2 If you answered **no** above (3.1), to what would you attribute your adherence to ARV treatment?

Treatment buddy		1
Support group		2
Family support		3
Church support		4
Support from friends		5
Community organisation	Specify	6
Disclosed status		7
Other	Specify	

3.3 If you answered **yes** above (3.1), to what would you attribute these challenge(s) to ARV treatment adherence?

Stigmatisation		1
Quality of care		2
Poverty (unbalanced diet)		3
Undisclosed status		4
Conflicting cultural views e.g. religious and cultural beliefs, worldview		5
Poor doctor-patient relationship		6
Other	specify	

4. Community Affiliation

Member of treatment buddy		1
Member of support group		2
Member of community	Specify	3
None		4
Other	Specify	

ART Patients Focus Group Questionnaire

General Information

Date of interview	
Venue	
Language	
Number of informants	

Patient's ARV treatment explanatory models

- **How would you explain (in your own words) your understanding of the ARV treatment?**
- **What role do your cultural beliefs (worldview, life experiences etc) play in your understanding of the ARV treatment?**
- **How does the medical doctor's explanation of the ARV treatment differ from your own understanding?**

Treatment perceptions and beliefs

- **What is your opinion about the government's ARV treatment programme?**
- **What are your cultural perceptions (worldview-values and attitudes) of the treatment?**
- **What are your cultural beliefs (religious beliefs, life experiences etc.) concerning the ARV treatment?**
- **Own treatment perceptions**

Treatment experience

- **Since commencing with ARV how's the treatment of the following people been like?**

    - **Community**
    - **Colleagues**
    - **Church**
    - **Neighbour**
    - **Relative (siblings, extended family)**
    - **Friend (Family friend)**
    - **Household**
    - **Parent (Mother, Father or both)**
    - **Partner**
- **Since commencing with ARV treatment, how would you describe your socio-cultural context?**
- **How did ARV treatment change your cultural ascribed status as a male/female in the household and broader community?**
- **What was your initial expectation about the effectiveness and toxicity (quality) of the ARV treatment?**
- **What is your actual experience with ARV treatment?**
- **What is the impact of ARV in your daily life?**

Medication adherence

- **In your own opinion which socio-cultural factors (family network, support structures, belief system, worldview, values and norms, individual perception) facilitate adherence to medication?**
- **In your own opinion which socio-cultural factors (family network, support structures, belief system, worldview, values and norms, individual perception) act as barriers to medication adherence?**

Care and support

- **What according to you will best describe an environment of care?**
- **What according to you will describe an environment of support?**

The role of traditional healers

The is an increasing believe among some people that traditional healers has a role to play in the treatment of HIV/AIDS. Despite that other people still hold strongly that traditional healers cannot help in the treatment of HIV/AIDS.

- What is your take on that?
- Why do you think so?
- Would you consider visiting the traditional healer, to verify your beliefs and perceptions?

General comments