

**A QUALITATIVE ANALYSIS OF THE COMMUNICATION PROCESS BETWEEN
HIV-POSITIVE PATIENTS AND MEDICAL STAFF: A STUDY AT STANGER
REGIONAL HOSPITAL'S ANTIRETROVIRAL THERAPY CLINIC**

by

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DECLARATION

I declare that: **A QUALITATIVE ANALYSIS OF THE COMMUNICATION PROCESS BETWEEN HIV-POSITIVE PATIENTS AND MEDICAL STAFF: A STUDY AT STANGER REGIONAL HOSPITAL'S ANTIRETROVIRAL THERAPY CLINIC** is my own work, that all sources that I have quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted before for any other degree at any other institution.

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Signature

Date

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SUMMARY

Health communication is a vital part of health care and treatment. For patients living with HIV, effective health communication is crucial. This study aimed at describing health communication from the perspective of HIV-positive patients by uncovering their experiences as they interacted with various medical staff members at Stanger Hospital. Guided by a review of various health communication models, data were collected via individual interviews and non-participant observation. The findings showed that interactive communication was favoured by all the respondents, especially communication that was patient-centred. Such communication encompassed education on how to live and cope with HIV. Obstacles to effective communication such as power differentials, lack of time and privacy at public health care clinics were identified. The study found that the different medical staff members at the clinic to various degrees addressed distinctive communication needs of HIV-positive patients. This study contributed to effectively understating the communication process as a whole.

Key words

ARV drug treatment; health communication; HIV and AIDS; interactive communication; interpersonal communication; medical professionals

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Anti-retroviral therapy
ARV	Anti-retroviral
BPs	Blood pressure
HBM	Health Belief Model
HIV	Human immunodeficiency virus
KIM	King Interaction Model
KZN	KwaZulu-Natal
NGO	Non-governmental organisation
OPD	Out-patients department
PLWHIV	People living with HIV
TB	Tuberculosis
UNAIDS	United Nations Agency for International Development
URERC	UNISA Research Ethics Review Committee
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

According to statistics, in 2008 an estimated 5,2 million people were living with HIV and AIDS in South Africa (Avert 2010:1). UNAIDS, however (2008:3), points out that, in 2008, there was a slowdown in HIV-infection rates in South Africa.

In order to address HIV/AIDS as a public health concern, the South African government has implemented a strategy of voluntary counselling and testing (VCT) for HIV, which is made available at hospitals and clinics. This VCT strategy encourages patients to be tested for HIV and to be counselled before and after testing. VCT is therefore the entry point to communication between the counsellor, nurse and/or doctor, and the patient. According to UNAIDS (1999:37), *“HIV counselling and testing has long been valued as a strategy for providing psychological support, especially to infected individuals”*. VCT services thus assist HIV-infected patients to cope with their disease.

In developing countries, VCT services have been introduced on a large scale in order to educate people about *“HIV risk behaviour”* (UNAIDS 1999:37). Owing to advances in antiretroviral therapy (ART), persons diagnosed as HIV-positive can manage their disease, as ART regimens help many people living with HIV to live longer and healthier lives. However, ART regimens are complex and have specific prescriptions regarding the timing of doses, as well as patients' intake of food and water. If patients do not take antiretroviral (ARV) medications as prescribed, or fail to adhere to their treatment, it may result in the clinical failure of ART and/or the transmission of resistant strains of HIV (Roberts 2002). Thus, complete adherence to ARV regimens is crucially important.

This study was an attempt at discovering how communication can assist or hamper patients in developing a better understanding of HIV and AIDS, and in enabling them to cope with the disease and to take ARV medication as indicated. The research thus focused on analysing the way in which the patient interacted with the different

medical professionals who made up the ART treatment team. The intention was to look at the influence of power differentials inherent in these interactions. The reason for this is that, from a biomedical hegemonic point of view, the doctor is regarded as the expert and the one who always knows best. Erger, Grusky, Mann and Marelich (2000:259) state in this regard that *“power and status have strong effects on communication, and this is especially true in the healthcare arena”*. Power differentials exist in the relationship between the patient and the medical staff as a result of a lack of biomedical knowledge on the patient’s part or the inability (actual or perceived) of patients to voice their opinions. It can be argued that the patient experiences the disease (and thus is an expert in experiential knowledge of the disease), whereas the doctor can only provide an external, biomedical point of view for treatment purposes. This inherent imbalance may disempower the patient in the treatment process. This point is reiterated by Wright, Sparks and O’Hair (2008:10), who state: *“By focusing primarily on physical causes of illness, the biomedical approach does not always take into account psychosocial aspects of illness, such as cultural norms, coping abilities, and life events that may interact with physical health problems”*. A detailed explanation of the above discussion on power differentials displayed by medical doctors can be found in the Chapter 4, under sub-heading 4.5.2.1. An explanation in the form of a thematic analysis is used to clarify the patients’ communication experience with the medical doctor relating to the above-mentioned biomedical hegemonic medical approach to patient treatment and care.

If a patient’s psychosocial needs are not addressed, treatment adherence may suffer. This is clearly pointed out by Wright *et al* (2008:10) when they argue that: *“allegiance to this approach may result in a number of problems, including failure to recognise how features of a patient’s day-to-day world (such as cultural beliefs, support networks, and financial status) may lead to their inability to comply with recommended treatments”*.

Patients may thus be disempowered as a result of the communicative rules operating in the medical system they enter for treatment, which allow only for a one-way flow of communication from the medical experts who adhere to a pre-set biomedical treatment plan. This point is clearly outlined by Lupton (1994:56), who maintains that: *“communication is largely regarded as a ‘top-down’ and somewhat*

paternalistic exercise, in which those with the medical or public health knowledge, whether they be physicians, other health care professionals, or health educators, perceive their role as disseminating the 'right' message to the masses for their own good".

Lau (2002:372) reiterates the fact that patients are disempowered in a treatment system that considers them to be non-compliant in terms of this system when they do not adhere to treatment medication. From a biomedical-hegemony point of view, all forms of patient resistance must be removed in order to adhere to the biomedical treatment system.

The shock and fear that a patient might experience when diagnosed with a serious illness can also render the patient subservient to the prescripts of a biotechnical treatment of their disease. According to Lupton (1994:59) *"many patients rely on their fate and trust in doctors to cope with illness, preferring to hand over responsibility for the management of the illness to the doctor. Uncertainty, when awaiting the help of a doctor to alleviate pain and provide reassurance, means sheer physical and psychological vulnerability on a scale that is rarely replicated in other social relationships between virtual strangers"*.

Medical professionals are always considered to be in a superior, more knowledgeable position than the patient, thus uncertainty and the feeling of being inferior to the medical personnel will always persist in this *top-down* relationship. In this regard, Babrow, Kasch and Ford (1998 in Wright *et al* 2008:30–31), for example, state that *"uncertainty during times of illness and when visiting the doctor can stem from many sources, such as the technical language and discourse used by physicians, the known potential for mistakes by the healthcare provider, and the stress of gathering accurate information while attempting to stay positive when coping with an illness"*.

Patients without access to private medical aid may be forced to adhere to the prescriptions of the treatment teams at public health care facilities for ART. Treatment adherence is a complex, context-bound phenomenon and, in this regard, cognisance should be taken of the fact that South Africa's current public health care

system is embedded in a political history characterised by inequality (Walker, Reid & Cornell 2004:61). Poverty is rife and infectious diseases, such as tuberculosis (TB) and HIV infection, are endemic in South Africa. In this regard, Walker *et al* (2004:61) note that “*South Africa is a classic ‘high risk situation’ – a phrase coined to describe a context in which HIV/AIDS will thrive*”. Moreover, a system of institutionalised racism under apartheid influenced the course and nature of the HIV transmission pattern in South Africa. Even after South Africa became a democratic country in 1994, treatment facilities for HIV and AIDS were still limited in government hospitals. In addition, ART was not readily available until recently and most people living with HIV (PLWHIV) in South Africa cannot afford private health care.

After the South African government agreed to roll out ARVs in the public health sector in 2003, the need for ART increased daily (Balwanth 2009) and government expenditure increased substantially in response (Balwanth 2009). However, the success of the ARV roll-out and adherences to treatment depend on communication, which facilitates the correct usage of the drugs.

Thus, the goal of this study was to analyse communication sessions between HIV-positive patients and a pharmacist assistant, a VCT counsellor, a doctor, a social worker and a nurse with the intention of discerning how that communication facilitates or hampers the understanding of the disease, as well as the correct usage of ARVs. Research has shown that, as a result of poor adherence to treatment regimens, “*the total lost benefits of ARVs are at least 3.8 million person-years for the period 2000–2005*” (Chigwedere, Seage, Gruskin, Lee & Essex 2008:1). When patients do not adhere to their medication the treatment value is lost in terms of enabling the patient to reduce their viral load, increase their CD4 counts and fight opportunistic infections (Godwin Rabkin & Chesney 2006:64). It can also be argued that the government loses out financially in terms of public health expenditure if the medication regimen is not adhered to by the patient (Wanjohi 2009).

1.2 BACKGROUND TO THE PROBLEM

In this section, the context of the research problem is discussed by first considering differential access to ARVs, then describing the situation of public health care at the

chosen research site and finally considering the communication process as a context for the research conducted.

1.2.1 Differential access to ARVs

Non-governmental organisations (NGOs) and activists are campaigning to make ART a human right for all PLWHIV. The World Health Organization and the Joint United Nations Programme on HIV/AIDS (WHO/UNAIDS) has developed a “3 by 5” initiative with the goal of having 3 million people on ARVs by the end of 2005. This initiative states that free access to ARVs has to become a basic human right in order to combat this disease. The plan is to address this health crisis in terms of a *“human-rights based-rather than a market-based-approach”*, since this pandemic is concentrated in poor communities where basic health care and treatment are not readily available for affected communities (Mukherjee 2004:1071). However, research by the WHO has indicated that *“ARV treatment coverage remains limited at 15% in developing and transitional countries and even lower in sub-Saharan Africa, at 11%. Universal access is still very much a distant goal”* (Jones 2005:77–78). Medication is not provided equally to all countries and is not equally distributed to all who need it in individual countries, for example, in Zambia medication is not readily available to the poor (Jones 2005:79). According to Cullinan (2002:761), poor countries require ART but issues of finance with regard to the drugs have intervened, thus ART is more available in *“industrialised countries, which bear only 5% of the global burden of HIV/AIDS”* (WHO 2003:1).

1.2.2 Public health care at the chosen research site

The data gathering for this study was undertaken at an ARV clinic based at the Stanger regional hospital. Stanger is an urban area in the South African province of KwaZulu-Natal (KZN), but most of the patients who attend the hospital come from the surrounding rural areas (Duze 2009). According to the UNAIDS/WHO (2003), in terms of HIV-infection rates among adults (15 to 49 years of age), surveys conducted in South Africa show that there are higher HIV-infection rates in urban areas than rural areas. However, the difference between the two categories is not

very large. Urban areas recorded adult HIV-infection rates of 10,6%, while rural areas throughout South Africa recorded rates of 9,4%.

In the wake of the South African government's approval of ARVs, VCT services and ARVs have over the years become accessible at most public health care facilities and, even in rural locations, most public clinics have evolved to provide VCT services. However, public clinics in remote areas do not necessarily have social workers and psychologists available on site, and if an HIV-positive patient requires these services he or she is usually referred to a nearby hospital. This is the case at Stanger regional public health care clinics. Thus, the hospital's ARV clinic is visited by about 100 patients a day on average (Duze 2009).

1.2.3 The communication process as a context for the study

When considering the communication process as the micro-context for this study, it was assumed that two-way communication was required when a patient was placed on a treatment plan, and that the medical treatment team needed to focus on achieving this goal. According to Erger *et al* (2000:259): *"Meetings between patients and health care providers are situations where the task is primarily one of communication. The patient tries to explain his problems and the health care provider tries to explain what can be done about those problems. Given that these interactions are where much of the work of health care gets done, where diagnoses are made and treatments prescribed"*.

In addition Roberts (2000:477) concludes that: *"in order to help HIV-positive patients adhere to the antiretroviral treatment regimes, it has been suggested that health care professionals spend time communicating with patients about the risk and benefits of the medications before patients embark on therapy, and provide routine check-ins regarding adherence issues after therapy is initiated"*.

However, barriers exist when attempting to achieve the goal of an egalitarian exchange of information in the treatment communication process. This is because the hegemony of biomedical knowledge tends to hamper a fully interactive process owing to its conventional one-way flow of information. Such a hierarchical one-way

communication process positions the patient as a docile body or passive agent under the clinical gaze and surveillance, and thus the control, of a powerful biomedically trained expert (Bury 1998:5–9). This is further fuelled by a belief in medical interventions as being the only appropriate vehicle for the control of disease. In this sense, public health concerns are medicalised and one-sided biomedical approaches to “control” morbidity and mortality are implemented. Technical knowledge is championed and used for instrumental action, and the PLWHIV, as the expert who has actual lived experience of what it is to be HIV-positive and to use ARVs, is silenced.

1.3 HISTORICAL OUTLINE OF HEALTH COMMUNICATION

Health communication as a field of study has become a necessity owing *“to a variety of communication problems that commonly occur within healthcare settings”* (Wright *et al* 2000:19). Often patients do not understand medical professionals or are too afraid or intimidated to ask questions and thus treatment effectiveness is lost. In the light of the rising increase in AIDS-related disease, health communication is a very important aspect to consider. According to Roberts (2000:477), *“decades of social and behavioural research suggest that this sort of provider-patient communication can have powerful effects on patient adherence to medication regimens”*. This interactive communication process is vital for patients if they are to adhere to ART and to ensure that treatment effectiveness is achieved.

According to the *South African national antiretroviral treatment guidelines* (South African Department of Health 2004:33), there are various strategies that need to be followed in order to promote adherence to ARVs. These include the need to educate the patient effectively. The working out of a treatment pattern with the patient links directly to the aspect of interactive communication whereby both parties negotiate and interact to reach common goals. Roberts (2000:482) supports this view when she states that *“without adherence communication, patient’s chances of success with the antiretroviral medications are diminished”*.

As HIV-infection rates increased in South Africa, the need arose to educate people about the disease and encourage them to be tested and to know their HIV status.

After ARVs were made publicly available in most public hospitals, it became necessary to educate people on how to adhere to medication regimens, as well as cope with the disease. Patients who are HIV positive and who required ART need to be encouraged to adhere to their medication; thus communication needs to occur between the pharmacist assistant, the nurse, the doctor, the social worker, the VCT counsellor and the patient.

At the Stanger provincial hospital a pharmacist assistant hosts scheduled training sessions with HIV-infected patients when they are put on ART. The assistant has to educate and explain to the patients how the treatment process works and to address any patient concerns (Balwanth 2009). Social workers at the hospital deal with the social problems that affect the patient and also facilitate social grant applications. In addition, the VCT counsellor performs ongoing counselling to help patients diagnosed as HIV positive. They also do pill counting and treatment adherence counselling for people on ART. Currently, some hospitals, including Stanger Hospital, have developed communication sessions with their patients called “drug literary sessions”, during which lectures are given in order to educate patients on HIV/AIDS in general. Various medical professionals engage in these sessions with the intention of educating patients on HIV/AIDS (Moodley 2009).

1.4 THE CENTRAL RESEARCH QUESTION

The central focus of this study was to answer the question: How does the communication process facilitate or hamper a better understanding of HIV and AIDS and of the prescribed treatment regimen for the individual patient living with HIV and accessing ART at a public health care facility?

Thus the thesis that guided this study was the need to understand how the practice of communication about HIV and AIDS in a hospital setting either facilitates or hampers patients’ understanding of how to live with the disease and of to use of ARVs.

1.5 THE RESEARCH PROCESS

To answer the central research question, the following 5 steps were followed in the research process. Although they are listed as linear steps below, the researcher followed a qualitative orientation in which these steps intermingled.

- 1- Understanding how the practice of HIV and AIDS communication either facilitates or hampers patients' understanding of their disease and the correct use of ARVs.
- 2- Literature review: three health communication models,
 - Health Belief Model (HBM)
 - King Interaction Model (KIM)
 - Therapeutic Model: Additional theoretical insights
Empowerment theoretical insights
- 3- Methodology: qualitative case study design
 - Methods include
 - in-depth interviews
 - observation
- 4- Analysis and representation of findings: thematic analysis
- 5- Conclusions and recommendations

1.6 OBJECTIVES OF THE STUDY

The sub-questions stemming from the central research question were the following:

1. How does interactive communication facilitate or hamper patients' understanding of HIV, AIDS and ARV drug treatment?
2. How does the patient communicate/interact with the different medical staff?
3. Which factors facilitate and which factors hamper an open sharing of information?

1.7 RATIONALE FOR THE STUDY

Health communication has over the years become an integral part of the sociological understanding of a patient's health and wellbeing, and if communication is not interactive or properly understood a patient's treatment can be at risk (Roberts 2000:477). The researcher is of the opinion that if appropriate communication does not exist, the efficacy of ART can be compromised and drug resistance may occur if treatment adherence is not observed. This view is supported by Mechanic (1998: xii), who states that:

“many persistent problems in medical care arise because of failures in communication with patients and their families, ambiguity of authority, breakdowns in communication and coordination among professional caretakers, and poor teamwork”.

Communication is a process and can be defined as *“the transmission or exchange of information and implies the sharing of meaning among those who are communicating”* (Thomas 2006:1). Health communication aims at merging health and communication to ensure that patients receive effective health care and treatment. Communication in a health care setting is also influenced by the power differentials that exist between medical staff and the patient; these unequal power relationships can also influence patient treatment. This view is also pointed out by Erger *et al* (2000:259), who state that:

“there are many factors that influence the interaction between patients and health care providers and the decisions made during these meetings. These factors include, but are not limited to, communication, power status, and perceptions of the likeliness that the patient will comply with treatment”.

Miscommunication can affect a patient's entire treatment process and cause great harm to the individual. This is pointed out by Wright *et al* (2008:20), who state that *“how providers and patients communicate in health care settings can potentially impact physical and psychological health outcomes, and problems such as medical errors and malpractice suits”.* Thus a need for this research exists and will be beneficial for future patients entering the health care system for ART at Stanger Hospital.

1.8 THE CHOSEN RESEARCH DESIGN AND METHOD

A qualitative research design was the method chosen to collect and analyse data for this study. The specific data-gathering techniques that were used by the researcher include observation and in-depth interviews. Participants were purposively selected with the help of the VCT counsellor; however, participation in the study was completely voluntary. Participants who were willing to participate in the research signed a consent and indemnity form to allow the researcher to record observations and discussions.

A qualitative research design was chosen for this study owing to the nature of the design and its ability to obtain rich, in-depth information from participants. The researcher realised that, in order to analyse health communication, one needs to interact with the patients and be available at the hospital to observe and synthesise data, hence, a qualitative orientation was best suited for this study. The data-gathering approach chosen was also guided by the specific choice of theoretical perspectives which included the various health communication models, namely, the Health Belief Model (HBM), the King Interaction Model (KIM) and the Therapeutic Model. Constructs from the three models were selected and were used as synthesising concepts in the field. This method ensured that data came to the researcher in an open, yet flexible, manner. Theoretical insights of empowerment were included to analyse patient and health care provider relationships. Chapter 3 of this dissertation contains a detailed discussion of the researcher's chosen methodology.

1.9 DEFINITION OF KEY TERMS

1.9.1 Interactive communication: for the purposes of this study, will be defined as intersubjective, patient-centred communication (Bury 1998:5–9).

1.9.2 Health: is defined and understood as a condition achieved when a patient experiences *physical, social and mental wellbeing* and is not merely free from disease (WHO 2007).

1.9.3 Communication: is defined as an exchange of messages or information between two or more people. It refers to the process of encoding and decoding messages between different people. Information is sent and is interpreted accordingly (Smith 1992:4).

1.9.4 Interpersonal communication: a two-way flow of communication which, for the purposes of this study, will be analysed in terms of patient–provider relationships (Northouse & Northouse 1985: 20).

1.9.5 Biomedical ethics: refers to traditional western medical treatment systems where the doctor is viewed as the superior treatment provider in the patient–health care provider relationship (Gillick 1985; Sharf & Vanderford 2003:103, in Wright *et al* 2008:103).

1.9.6 Health care professional: represents the different treatment team members who interact with the patients and either facilitate or hamper the individual’s understanding of HIV and AIDS and ARV medication.

1.9.7 Interactive communication process: for the purposes of this study, refers to the communication that occurs between the medical team members and the patients during the individual medical treatment sessions and the group lectures.

1.10 OUTLINE OF THE DISSERTATION

Chapter 1 of the dissertation contextualises the study by providing information on the background to the research problem, the historical background to health communication, the statement of the problem, the rationale for this study including a discussion on the objectives of the study, as well as the research design and method used for this study. Chapter 2 provides a detailed discussion by reviewing the existing literature and explaining the various health communication models the researcher has chosen for the study. Chapter 3 explains the research methodological approach the researcher followed for this study, while Chapter 4 provides an in-depth analysis of the research findings and links them back to the

theoretical background explained in Chapter 2. The dissertation concludes with Chapter 5 in which some concluding remarks and recommendations are made.

1.11 CONCLUSION

This chapter provided detailed information on the background to the study conducted. The next chapter reviews the body of existing literature and places the study in context.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter introduces the theoretical framework used for this study. Three models that describe health-related behaviour and decision making were reviewed, namely, the Health Belief Model (HBM), the King Interaction Model (KIM), and the Therapeutic Model of interpersonal health care. Each model describes different theoretical concepts pertinent to the study. The researcher used these concepts eclectically as sensitising devices for her study, which was intended to investigate the interactive health communication process at Stanger Regional Hospital between various medical team members and HIV-positive patients receiving ART. In addition, insights gleaned from a review of patient empowerment theory were deemed necessary, since the study problematises the notion that health communication is a one-way process, flowing only from the medical expert to the patient. In conceptualising and theoretically locating the study, the researcher remained cognisant of the fact that the goal of the study was not to predict human behaviour, but rather to describe and create an in-depth understanding of behaviour patterns. This meant that the researcher had to apply theoretical insights to her chosen qualitative research orientation.

This chapter outlines the way in which the selected theories were used in the field of HIV and AIDS research. Information is provided here in great detail in order to locate the study in the context of previous research conducted. A discussion on the three health communication models chosen is provided and a description of the selected tenets in this regard is given, linking the selected constructs to the study conducted. Finally, empowerment theoretical insights are explained to indicate how patients can be empowered in the health care system.

2.2 RESEARCHERS' USE OF THE SELECTED MODELS AND THEORIES TO STUDY HEALTH BEHAVIOUR

The information provided below outlines recent research conducted in the field of health communication. The researcher wishes to point out that most of these studies

made use of a quantitative research methodology, which differs from the qualitative research orientation she chose. However, the theoretical constructs used in these studies were applied as heuristic devices, thus allowing the researcher to gather data inductively in the field, consequently adhering to the flexible nature of the chosen qualitative research design. The focus of this study was not on the individual but rather on the communication process in terms of whether it either facilitated or hampered patients' ART adherence.

2.2.1 Application of the Health Belief Model (HBM) in the field of health behaviour and communication

A review of recent studies in this field revealed that the HBM has been used to analyse patient behaviour patterns and their changes with regard to health care and treatment in HIV and AIDS. For example, Mattson (1999:240) used the HBM to analyse the relationship between HIV counselling and patients' agreement to practise methods of safe sex. In this regard, the current study aimed to emulate Mattson (1999:240) by using a coding scheme that was inductively derived to explain the interpersonal relationships that were built up during patient and medical professional counselling sessions. Mattson (1999) analysed taped sessions and allowed the data as per the tenets of the model to come to the researcher inductively from the structured questionnaire. The coding scheme the researcher used was inductively derived from the tenets of the different health communication models namely, the HBM, the King Interaction Model and the Therapeutic Model. An explanation of the sensitised codes/tenets can be found in Chapter 3. In this chapter the researcher explains which codes/tenets from these communication models were used to develop the observation schedule and the interview schedule. In Chapter 4, a detailed explanation is provided for each theme; these explanations are linked to the tenets of the models selected.

Helman (1985:923) used the theoretical framework of the HBM to analyse communication between a doctor and a patient. The model was used as a framework catering for the patient's perspective. According to Helman (1985:924), the HBM "*has been used to predict, and explain, the incidence of non-compliance*" in patients with various medical conditions. This study was conducted over a period of

six months with 42 patients, 12 doctors and six nurses (Helman 1985:924). Data were collected and analysed quantitatively using semi-structured interviews and structured questionnaires. The study concluded that medical professionals must be aware of patients' perceptions of their illnesses in order for communication to be effective and for the goal of effective health care to be attained.

Quah (1985:351) researched the HBM in order to analyse health behaviour specifically in the context of cancer, heart disease and tuberculosis. Of particular interest is Quah's (1985:351) criticism that the HBM does not offer a culture-free analysis of health behaviour. This was taken to heart by the researcher and underscores her choice of a research orientation that locates behaviour, decision making and communication in a particular context – a context in which culture is assumed to have a great influence on people and their behaviour. The HBM does not cater for an individual person's cultural background or how this can effect treatment and care when dealing with a patient who is diagnosed as HIV positive. Thus, when linked to a South African context, culture forms a prominent part of most people's lives, especially when related to health care and treatment. This argument will be developed in more detail in the section that deals with criticism of the chosen theoretical frameworks.

Crepaz and Marks (2002:135) analysed sexual risk behaviour in HIV-positive patients and reviewed various studies that examined "*psychological, social, interpersonal, and medical variables*" using a mixed design. Meanwhile, Munro, Lewin, Swart and Volmink (2007:16) analysed the way health behaviour theories assist in promoting medication adherence on a long-term basis for TB and ARV medication, using concepts from 11 different behaviour change theories. These two studies (Crepaz & Marks 2002 and Munro *et al* 2007) thus provide an example of how eclectically selected theoretical notions from various models can be combined to form the basis of a theoretical framework for a study.

2.2.2 Application of the King Interaction Model (KIM) in the field of health behaviour and communication

The KIM, which King calls the *Model of Transactions*, was developed in 1971 and eventually evolved into the *Theory of Goal Attainment* in 1981 (King 1996:62). This model is ideal for analysing communication on an interpersonal level from the patient's perspective, since it depicts a scenario in which both the nurse and the patient need to work together to maintain health. The tenets of this and other models are discussed further on in this chapter. In the section below, studies that used this model are reviewed.

Edwards, Peterson and Davies (2006:3) researched the way in which nurses' improved communication skills five months after following a multiple component intervention that led to the establishment of therapeutic relationships. These researchers explain how important interactive communication is in establishing and maintaining effective health care. A quantitative orientation was used where nurses were randomly selected and their responses audio taped and transcribed. Results concluded that nurses need to communicate effectively in order to maintain effective nurse–patient relationships in health care (Edwards *et al* 2006:10).

Mok and Chi Chiu (2004:475) analysed the interactive communication process between nurses and patients using a qualitative design. The study concluded that *trust* is essential in the relationship between the patient and the nurse. When trust is mutual in a relationship, the goal of health care is achieved (Mok & Chi Chu 2004:475).

Haskard, DiMatteo and Heritage (2009:21) analysed nurse–patient satisfaction in primary care interactions and studied the way verbal and non-verbal communication impacted on interactive communication during post-visit sessions. A quantitative research orientation was followed using questionnaires. Sessions with the nursing staff were also videotaped and analysed for verbal and non-verbal cues. The results concluded that both the patient and the nurse need to work together to maintain health-related goals (Haskard *et al* 2009:28).

Battaglioli-DeNero (2007:18) researched different ways in which adherence to therapy can be improved and, accordingly, notes that three aspects promote treatment adherence. These include aspects related to treatment; aspects related to interpersonal relationships between the patient, the treatment team and the health care system; and aspects related to the individual patient. This therefore emphasises that interactive communication is essential in the health care system in order for patients to be adherent to ART. Battaglioli-DeNero (2007:19) concludes that time is a negative factor in the medical system since many medical staff do not have sufficient time to provide individual attention and detailed adherence counselling to patients. The study pointed out that in a health care system nurses tend to spend more time and interact more with HIV-positive patients than doctors, thus these medical professionals are in a better position to educate the patient on ARV adherence strategies (Battaglioli-DeNero 2007:21).

2.2.3 Application of the Therapeutic Model to the field of health behaviour and communication

Seminal work on the application of the Therapeutic Model was carried out by Smith (1985:79), who points out that morals and ethics are essential in a therapeutic relationship. Jonsen (1983 in Smith 1985:80) concurs, noting that honesty on the part of both participants is required in the shared relationship between medical professional and patient. It can thus be concluded that therapeutic communication includes a two-way relationship during which interactive communication must occur between the medical professional and the patient. Moreover, trust must be present in this relationship if treatment success is to be ensured.

Lyons (1997) analysed ARV drug adherence in situations regarded as special, including substance abuse and homelessness, by using various theoretical models. According to Lyons (1997:32), in a therapeutic relationship the doctor is responsible for educating the patient on drug adherence, provided that the patient wishes him or her to do so. From this it can be gathered that communication has to exist on an interpersonal level in order for the two-way flow of communication to occur and to allow the patient's opinion in terms of being catered for, in order to achieve effective treatment adherence. In this study the issue of trust between the medical

professional and the patient evolves as a key issue in the maintenance of an effective therapeutic relationship in health care.

Neumann, Basing, Mercer, Ernstmann, Ommen and Pfaff (2009:339) analysed the effectiveness of clinical empathy using the Therapeutic Model. The results showed that, in order for success to be achieved in medical care, medical professionals must be empathetic towards their patients and this quality must be displayed during the interactive treatment sessions with the patient.

Davis, Foley, Crigger and Brannigan (2008) conducted a study to indicate from the literature how essential the therapeutic relationship is for maintaining effective health care for the patient. They reaffirm the importance of the interactive communication process and conclude that for patients to become more active in their own health care, health care providers need to improve their communication skills (Davis *et al* 2008:173).

2.2.4 Application of empowerment theory in the field of health behaviour and communication

Boehm and Staples (2002) analysed empowerment theory as it is understood by patients and social workers. According to these researchers, the literature does not address the patients' and medical professionals' opinions in treatment care (Boehm & Staples 2002:449). These researchers used a qualitative research design in which they allowed data to come to them inductively in the field. The study concluded that social workers need to listen to patients more in order to empower them; thus, in order to maintain health, this theoretical framework needs to shift empowerment towards the patient.

Beeker, Guenther-Grey and Raj (1998:831) conducted a study to research how relevant empowerment was for women with HIV when related to community interventions. This research defines empowerment in various contexts and aims at integrating empowerment theory into community empowerment interventions. The study clearly indicates how this theory can be used in the field of HIV and AIDS. According to Beeker *et al* (1998:836):

“the widespread adoption of empowerment as a guide to theory, practice, and research – there are trends suggestive of paradigm shift, including the increasing interest in the social and environmental determinants of HIV transmission”.

Aujoulat, d’Hoore and Deccache (2007:13) analysed the way empowerment as a definition has been used when related to educating and caring for patients with chronic illnesses. These researchers used a qualitative research design to analyse 55 existing articles. They found that empowering outcomes should be patient-specific, patient-centred and interactive. They conclude that empowerment theory *“is more often defined according to its anticipated outcomes rather than to its very nature”* (Aujoulat *et al* 2007:13).

2.3 THE MAJOR TENETS OF THE SELECTED THEORIES

This section provides a brief overview of the tenets of the various theories used in this study. Accordingly, the researcher demonstrates the way in which certain concepts were used as sensitising devices that allowed data to be gathered inductively in the field. The theoretical frameworks according to the selected tenet of each model were used flexibly in order to form a starting point from the literature, which guided the direction in which the researcher proceeded during the fieldwork. This allowed the researcher openness in the field and consequently adherence to the selected qualitative research design. According to Bowen (2006:3), sensitising concepts highlight important aspects of *social interaction* and cater for research in *specific settings*. This particular study was conducted in a hospital setting and thus these sensitising concepts allowed the researcher to analyse the social interaction between the patients and medical staff effectively. In this way the researcher was able to obtain data as she experienced them, thus satisfying the core aspect of the study which was to understand interactive health communication from the patients’ perspective rather than to predict it.

2.3.1 The Health Belief Model (HBM)

The HBM was developed from a socio-psychological framework according to which the focus is on the individual. According to Janz, Champion and Strecher (2002:45), this model allows for the conducting of research aimed at emphasising the individual and his or her *predictive qualities*. This central focus on the individual justifies the researcher's choice in selecting this theoretical framework, as HIV-positive patients entering the health care system for treatment belong to a specific socio-psychological category and have developed their own perceptions about their new illness and new behaviours for using ARVs effectively and living a healthy lifestyle.

The HBM's theoretical concepts focus on individual behaviour change. Janz *et al* (2002:45) point out that "*the HBM has been used both to explain change and maintenance of health-related behaviours and as a guiding framework for health behaviour interventions*". When patients enter the health care system for treatment, they are expected to work towards and maintain behaviour change, with the help of various medical professionals whose aim is to assist the individual patient to achieve the ultimate goal of adherence to ART. Consequently, for patients to cope with their new illness and to "live positively", a two-way flow of communication from the various medical professionals is required, informing them on how to use ARVs correctly. Furthermore, the patient needs to be advised and educated about the disease as well as adherence to the medication.

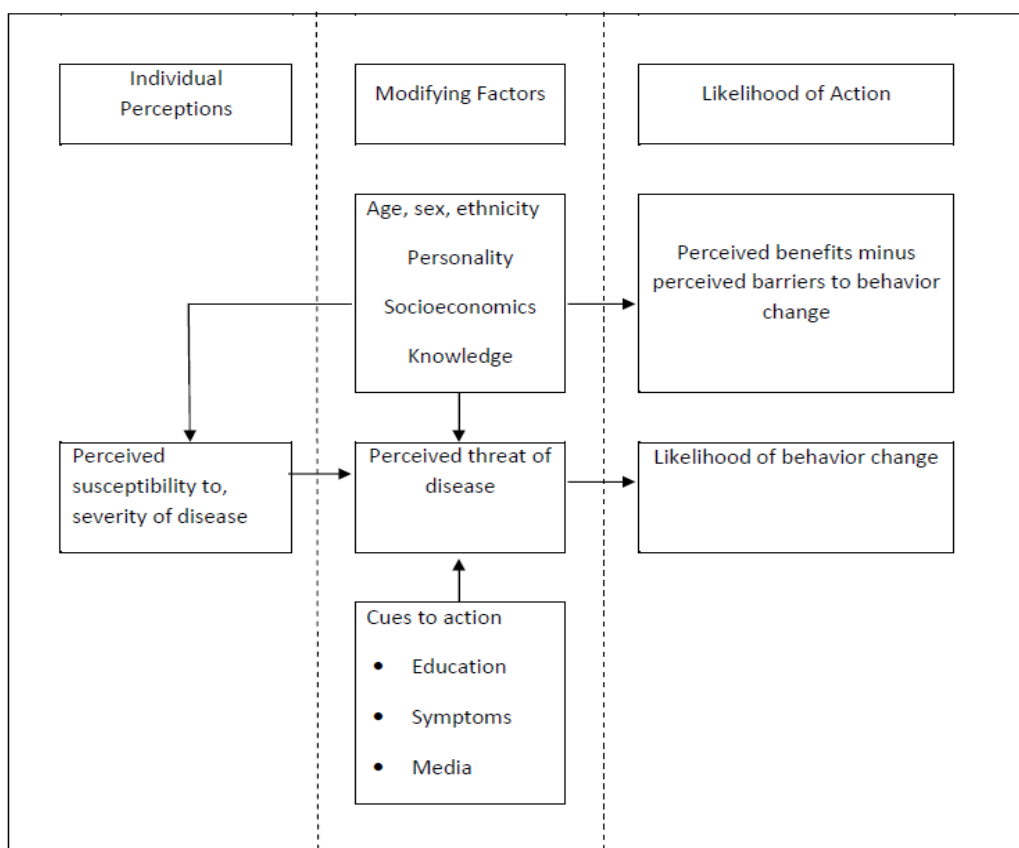


Figure 2.1: The Health Belief Model

Source: Janz & Becker (1984 in Glanz *et al* 2002:52)

In the following section, the key tenets and notions that make up the HBM as depicted in Figure 2.1 are discussed in greater detail.

2.3.1.1 Perceived susceptibility

Janz *et al* (2002:48) define *perceived susceptibility* as a concept that illustrates the way the patient accepts their new illness, that is, their personal view of their illness on a general level. Using this definition, the researcher analysed the way in which patients at the Stanger Regional Hospital accepted their illness. This information was gathered inductively during the session the researcher scheduled with the patient, with the intention of understanding how communication facilitated or hampered treatment. These observational sessions also provided data which allowed the researcher to unpack this perceived susceptibility.

2.3.1.2 *Perceived severity/perceived threat*

The construct *perceived severity/threat* is associated with the individual and his or her understanding of their illness in relation to how the illness will affect their life with regard to work, family and social relations (Janz *et al* 2002:48). This concept catered for the patients' individual perspective which is directly linked to the research questions stated in chapter 1, as the researcher wished to obtain the patients' perspective on the interactive communication process as either facilitating or hampering patient treatment and care.

2.3.1.3 *Perceived benefits*

According to Janz *et al* (2002:49), the concept *perceived benefits* relates to the patients' belief in consuming medication to reduce the seriousness of their illness. This concept sensitised the researcher to focus on the interactive sessions between the various medical professionals and the patients, and whether these sessions facilitated or hampered the patients' understanding of ART. Thus, in taking cognisance of this construct, the researcher aimed at gaining greater insight into individuals' perceptions of the potential benefits of ART adherence.

2.3.1.4 *Perceived barriers*

The construct *perceived barriers*, according to Janz *et al* (2002:48), relates to an "*action's expected effectiveness against perceptions*" which relates to, *inter alia*, the patient "*having negative side effects or iatrogenic outcomes*". Whereas perceived and actual side effects are important barriers to treatment adherence, two other factors also require consideration, namely cultural factors and the power differentials between the treatment staff and the patients.

In African countries poverty is rife and thus treatment access is limited. In the past, the availability of ART was limited owing to social, political and economic barriers that prevented access to treatment for all. As a result of public health inefficiency in Africa, drugs are only available through treatment programmes, NGOs and public health care facilities, and resources and funding are limited, resulting in reduced

access. As discussed in the introductory chapter and as will be elaborated later in this chapter, South Africa's historical context, particularly the apartheid regime, has shaped the medical treatment system that is available today. This is underscored by Nguyen, Ako, Niamba, Sylla and Tiendrebeogo (2007:34), who state that treatment adherence has to be holistically viewed taking into consideration the *social and historical contexts*.

In order to understand why a patient is adherent or non-adherent, certain social contexts have to be taken into consideration. In this regard, where communities are uneducated with regard to ARV treatment and its effectiveness, patients have less access and social conditions of stigma prevail that interfere with their perseverance to recover. In such circumstances, patients can be empowered through education in the treatment system, although their social conditions need to be taken into consideration when empowerment initiatives are planned. In cases where poverty is rife, patients need to be taken into consideration on a therapeutic level, analysed with regard to the nature of their access to medication and helped to overcome the challenges they experience in adhering to their medication regimens. Consequently, policies and programmes need to be created that cater for individuals on a local level (Nguyen *et al* 2007:34–35).

Culture is a major barrier to a patient's adherence to ART. People are generally governed by their cultural beliefs, which is particularly the case in Africa. As previously mentioned, however, the HBM does not specifically make reference to the role of culture in individual patients' diagnosis and the treatment of their disease. However, many patients' are influenced by their traditional beliefs which can include consuming herbal remedies to cure AIDS. This point is reiterated by Ware, Wyatt and Bangsberg (2006:20), who state that some Christians believe that God will cure a person of HIV/AIDS and not ARV medication. Traditional biomedical ethics imply that the doctor knows best and, consequently, the patient, who is the subservient party, might be afraid to inform the medical professional that culture affects their treatment process (Wright *et al* 2008:10). If, as a result of cultural and traditional beliefs, a patient is non-adherent to ARVs, this should be addressed by the medical professional.

2.3.1.5 Cues to action

The construct, *cues to action*, focuses on the ways in which the individual patient accesses information related to their new illness in order to become aware of their disease, and makes use of different methods to remind them to achieve medication adherence (Janz *et al* 2008:49). The researcher drew on this interpretation of this construct when observing and analysing drug literacy classes and adherence counselling sessions.

2.3.1.6 Modifying factors

This construct, *modifying factors*, explains the focus on the individual, since it encompasses the socio-psychological variables which, according to Northouse and Northouse (1985:19), are vital elements of communication interaction. Northouse and Northouse (1985:19) state that: *“patients failure to comply has been found to be related to communication patterns in which the health professional is described as formal, rejecting, or controlling; the professional strongly disagrees with the patient; the professional interviews the patient at length without allowing feedback, or engages in nonreciprocal interaction; and the health care worker fails to make clear the purpose of treatment”*.

The notion of *modifying factors* makes it possible to consider that patients come from different backgrounds. *Modifying factors* also play a part in the communication process about treatment and adherence. In this regard, Glanz *et al* (2002:50) note that *“sociodemographic factors, particularly educational attainment, are believed to have an indirect effect on behaviour by influencing the perception of susceptibility, severity, benefits, and barriers”*. Since the universe for observation (from which respondents could be recruited) included patients from the rural areas around Stanger, such potential research participants could be assumed to have lower levels of educational attainment (Duze 2009). This implies that power differentials between patients and medical professionals exist, which can make patients reluctant to ask questions, or mention problems. Consequently, inadequate communication that is not fully interactive can hinder treatment. This point is reiterated by Erger *et al* (2000:260): *“The health care provider seeks to take control over the patient’s*

problem, and what should be done about it. The focus during meetings is typically limited to medical issues. Social and personal factors are usually marginal to the task at hand”.

2.3.2 The King Interaction Model (KIM)

Constructs from the KIM were eclectically selected to contribute to the theoretical framework that was used to analyse the interpersonal relationship between a nurse and a patient. It can be argued that this model was intended to analyse the interpersonal relationship between a nurse and a patient only. However, after initial observation in the field, the researcher realised that the relationship that develops between an HIV-positive patient and a VCT counsellor is actually of a personal nature, since the VCT counsellor assists the patient in the treatment process from the very beginning. The model thus illustrates a two-way relationship and can be used to analyse other interpersonal communication processes in a health care system. According to King (1995:27), nursing is the interplay in a relationship shared between a nurse and a patient in the health care system. Therefore, the situation is such that the two individuals work together in an interpersonal manner to obtain the goal of effective health and wellbeing in the patient. The KIM, like the HBM, focuses on the individual.

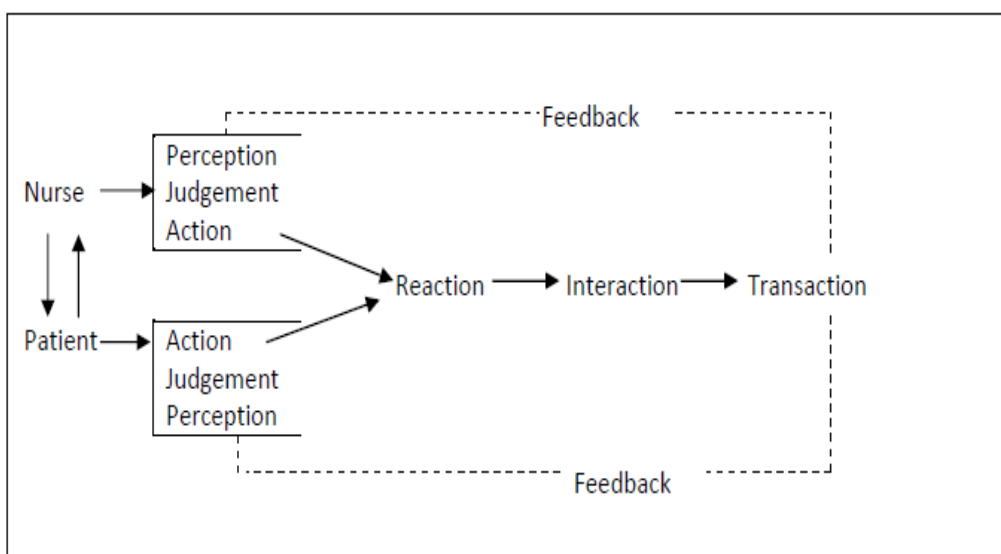


Figure 2.2: The King Interaction Model

Source: IM King (1971:92 in Northouse & Northouse 1985:21)

According to King (1971:92 in Northouse & Northouse 1985:20), the KIM analyses the two-way interactive communication flow between the nurse/VCT counsellor and the patient in the following way:

“In the interactive process, as a nurse and patient assess goals to be achieved, and mutually define health goals, a transaction occurs. This mutual agreement has an effect on the actions and judgement of the nurse and patient and influences each one’s perception. A series of these kinds of acts takes place as the nurse and patient interact in a nursing situation”.

In the health care system, when the nurse and patient interact with each other, an interpersonal relationship occurs and communication flows on a two-way level.

The notion of *judgement* in the model (Northouse & Northouse 1985:20) refers to the way in which the patient and nurse assess the situation and judge the positions they are in – both parties form *perceptions* of the case at hand. According to Northouse and Northouse (1985:20), when the nurse and patient make *judgements* about each other they display verbal or non-verbal *actions* that create *reactions* between them. The *feedback* concept enables interactivity to occur between the two parties ensuring that they are aimed at reaching related goals. The *interaction* construct refers to *“the reciprocal interplay between the nurse’s and the client’s perception, judgements, and actions”* (Northouse & Northouse 1985:20). The various constructs in the model are interlinked, thus the *interaction* construct will be defined according to the communication interaction that occurs between the nurse and the patient. According to the model, the *transaction* construct refers to the relationship created by the nurse and the patient as they work together in achieving *health-related goals* (Northouse & Northouse 1985:21).

2.3.3 The Therapeutic Model

According to Northouse and Northouse (1985:16), the Therapeutic Model displays the importance of *role relationships* with regard to medical professionals when assisting patients to adapt to their illness with the aim of becoming healthy again. The Therapeutic Model complements the KIM since the two models depict important

concepts related to the interpersonal communication between medical professional and patients. Like the HBM and the KIM, the Therapeutic Model is patient-focused and caters for the individual patient. These models complement each other in their contributions to the researcher's essential aim of analysing the interactive communication process that takes place with patients in the health care system.

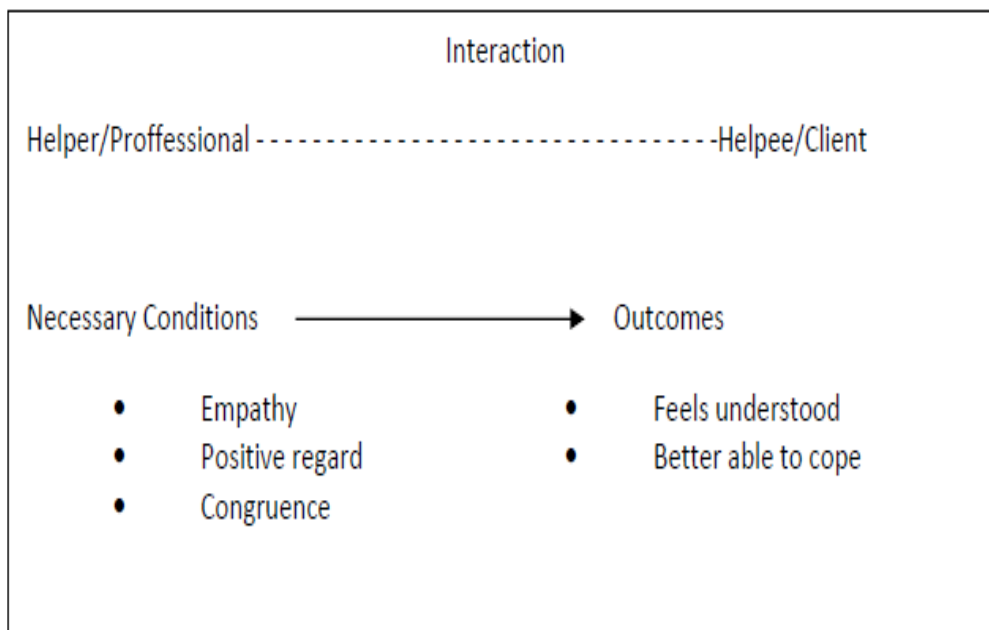


Figure 2.3: The Therapeutic Model

Source: Rogers (1951 in Northouse & Northouse 1985:17)

This model emphasises the relationship between the health care professional and the patient (client) during their interaction with each other in the health care setting. In such a setting, the health care professional must adhere to *necessary conditions* to ensure *outcomes* in the patient (Northouse & Northouse 1985:17). The *empathy* construct helps explain how the health care professional shares the patient's grief and displays understanding towards the patient. *Positive regard* is defined as the attitude that the health care professional displays towards the patient. Such a relationship should be one of tolerance and acceptance and these qualities should be displayed during the interactive sessions. According to Northouse and Northouse (1985:17) "*communicating congruence involves the honest expression of the helper's own thoughts and feelings*". The health care professional has to display *honesty* and trust towards the patient in order for communication to be *real* and

effective (Northouse & Northouse 1985:17). The constructs above clearly indicate how the health care professional needs to communicate with the patient in order to maintain health. In addition, the health care professional must adhere to the *necessary conditions* in order to achieve the desired *outcomes* which assist the patient positively (Northouse & Northouse 1985:17).

2.3.4 Empowerment theory

Empowerment theory posits that the medical professional can be an empowering agent in the patient's treatment process. According to Perkins and Zimmerman (1995:570) "*empowerment research focuses on identifying capabilities instead of cataloguing risk factors and exploring environmental influences of social problems instead of blaming victims*". The principle of this theory is that *social problems* that may affect ARV adherence can be addressed by viewing them from the patient's perspective.

Some insights of this theory were included to supplement the eclectically chosen constructs of the three models, since the research approach problematises the notion that health communication is one way and flows from the medical expert to the PLWHIV. Consequently, the insights of empowerment theory help to expand the theoretical framework in the direction of the patient and, thus, the theory enables an analysis of the power differentials that exist between medical professional and patient in the medical system and their affect on ARV adherence. In this regard, Perkins and Zimmerman (1995:570) state that "*empowerment-orientated interventions enhance wellness while they also aim to ameliorate problems, provide opportunities for participants to develop knowledge and skills, and engage professional as collaborators instead of authoritative experts*". Even though the medical professional holds great knowledge on the biomedical aspects of HIV/AIDS and ART regimes, the patient is the one actually living with the disease. Patients should be allowed to empower themselves in order to attempt to live positively. Accordingly, the medical professional and the patient can work together in a mutual two-way relationship to maintain the ultimate goal of effective health and wellbeing of the patient. According to Lau (2002:373), "*the goal of patient empowerment is to build up the capacity of patients to help them to become active partners in their own*

care, to enable them to share in clinical decision making and to contribute to a wider perspective in the health care system”.

2.4 CRITICISM OF THE CHOSEN THEORETICAL FRAMEWORKS

A major criticism of the HBM is that culture as a context for action is not included or catered for theoretically in the model. According to Quah (1985:363), *“the cultural differences among ethnic groups might prove crucial in the perception of seriousness and susceptibility to disease, as well as in the perception of social sanctions attached to a given disease. The HBM overlooks this cultural dimension”.*

The HBM has been used in many studies yet it is often noted that culture, which forms a vital aspect of health care and provider–patient relationships, is excluded from the model. In this regard, Schouten and Meeuwesen (2006:21) note that, in doctor–patient communication, culture is a vital aspect that needs to be included and discussed in this relationship as it is another *dimension* of the communication session. This interpersonal communication session is already a difficult task and the addition of culture as a topical issue adds to the difficulty of the situation.

In nursing care, there is a lack of knowledge and a certain amount of intolerance in terms of the treatment of patients’ from diverse cultural backgrounds. Duffy (2001:487) states that *“nurse and health care researchers continue to report disparities in health, an unequal distribution of health care, and the lack of knowledge and sensitivity when caring for clients from another culture”.* The Therapeutic Model also does not consider culture, although the role of empathy towards the patient is acknowledged. The empathy concept does not accommodate culture as such; it would seem that the medical professional merely feels sorry for the patient and aims to understand the patient better. Research by Airhibenbuwa and Obregon (2000:5) has shown that, for future HIV and AIDS prevention and care strategies, communicative methods must be emphasised and the importance of culture in relation to behaviour must be addressed in such strategies.

A more general concern, relating to the cultural-specificity of theoretical models, is articulated by Meleis (1991 in Carter & Dufour 1994:129), who points out that:

“critiques have published concerns about theory’s usefulness in certain situations, suggesting that usefulness is limited to cultures which share Western sick role attitudes”. Airhibenbuwa and Obregon (2000:9) agree in this regard and comment that most theories do not cater for the non-Western world, thus the cultural context is not given sufficient attention:

“Theories based on the individual, which maybe effective and meaningful in a Western context, have lesser relevance in self-efficiency cultures of Asia, Africa, Latin America, and the Caribbean. In these regions family and the community are more central to the construction of health and well-being than the individual, even though the individual is always recognised as an important part of the cultural context”.

The models discussed in this chapter therefore have limited applicability for understanding health behaviour and health decision making in a South African context. Walker, Reid and Cornell (2004:90–94) explain that *“South African society is characterised by cultural complexity and difference. This is reflected in the many ways that health and disease are understood ... it is believed that as many as 80% of African people consult traditional healers”*.

Empowerment theory enables an understanding of health promotion as being aimed at educating and empowering patients within the medical system. The definition of empowerment is not fixed, but rather contextually and situationally defined (Rappaport 1987 in Rissel 1994:39). According to Aujoulat *et al* (2007:18) *“empowerment may be defined as a complex experience in personal change”*.

Beeker *et al* (1998:831) state that the key notions of empowerment theory have become influential in HIV policy and programme research funded through the Centres for Disease Control and Prevention, but that the *“adoption of an empowerment framework for HIV prevention will require further theory and measurement development, as well as changes in how public health researchers and practitioners work with the communities they serve”*. Thus it can be gathered that, although an empowerment framework is being used, more research is required

since it can be assumed that the theoretical framework is well suited to an HIV health-care context.

2.5 CONCLUSION

This chapter provided a theoretical framework for the study and introduced recent work completed by fellow researchers in the field of health communication. The review of the literature was done in detail in order to justify the research design chosen for this study, as well as to locate the study in the context of previous research conducted. This chapter also aimed at explaining the constructs for the study, which were eclectically chosen from three health communication models. These constructs were then linked to the chosen research methodology in order to justify the method chosen for conducting the research. The information provided was integrated into the chosen research method to justify the choice of research design and, in addition, theoretical insights of empowerment theory were integrated into the theoretical framework to further explain how the patient can become empowered in the medical system when receiving ARV treatment. The chosen research methodology will be explained in the next chapter.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

In this chapter the chosen research design and the reasons for the selected methodology are discussed. In order to collect and analyse data for this study, a qualitative research design was chosen. The specific data-gathering techniques that were used include non-participant observation and in-depth interviews.

The chapter gives detailed descriptions of the research design and the site selected for the study. In addition, the data collection techniques, that is, the two methods of data generation, are discussed in detail. Subsequently, the way in which the researcher negotiated access to the hospital is explained. Furthermore, the sampling procedures and the criteria for inclusion and exclusion of volunteers for this study are discussed. Additionally, the way in which the data were analysed and interpreted is outlined and issues of reliability and validity are explored, ethical issues pertinent to the study are discussed and the information-gathering process outlined. Finally, the researcher explains how she carried out a process of triangulation in order to ensure credibility and validity in the data.

3.2 THE CHOSEN RESEARCH DESIGN

A qualitative research design was selected for this study. This was chosen because the researcher wished to analyse the interactive communication process between patients and medical professionals at the Stanger Regional Hospital in depth.

According to Denzin and Lincoln (2005:2):

“Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story,

interview, observational, historical, interactional and visual texts – that describe routine and problematic moments and meanings in individuals' lives".

The study followed an interpretative paradigm, in terms of which information was inductively gathered in the field. A basic assumption of the research was that patient-centred care needs to be studied from the patient's perspective, with the individual's needs specifically being taken into consideration. Therefore, another assumption that arises here is that a patient's health care regime is the product of collaboration between the patient and the health care professionals. Thus, treatment team members need to develop interpersonal relationships with the patients and create an atmosphere of trust during the various interactive sessions (Lambert, Street, Cegala, Smith, Kurtz & Schofield 1997:28).

Based on these assumptions, the researcher chose an approach that enabled her to gather and interpret data from the patients' perspective and to gain insight into the way interactive communication either facilitates or hampers patients' understanding of HIV and AIDS and ART. In adhering to a qualitative orientation, the focus of this study was not on predicting patient behaviour but rather on developing an understanding of the way interactive communication either facilitates or hampers a patient's understanding of HIV and AIDS and ART. A multimethod approach was used that included individual and in-depth interviews, and non-participant observation. A semi-structured interview schedule and an observation schedule were developed as data collection tools, with the semi-structured nature of these tools allowing for flexibility in gathering the data. Furthermore, the use of two methods allowed the researcher to triangulate her findings and thus ensure their credibility.

Studies by other researchers also aimed at analysing health professional and patient relationships have used similar research methods for collecting data. In this regard, Erger, Grusky, Mann and Marrelich (2000:259) used a qualitative research design in order to analyse two-way communication in great detail. In order to obtain rich data, Marelich, Roberts, Murphy and Callari (2002:18–19) also employed a qualitative research design to analyse AIDS patients' involvement in ART decisions. A qualitative design was also used by Herselman (1996:155), who analysed the communication barriers that exist in a multicultural clinic in South Africa. These

research studies help to justify the use of a qualitative research design for discovering rich data when analysing provider–patients relationships.

Although the three communication models (HBM, KIM and Therapeutic Model) selected are usually tested using quantitative research methods, the focus of this study was on an interpretive approach to health communication and not on the testing of a model. According to Neuman (2007:111) *“qualitative researchers primarily follow an inductive route. They begin with empirical data, follow with abstracts ideas, relate ideas and data, and end with a mixture of ideas and data”*. The chosen research design enabled the researcher to focus on the way in which interpersonal communication unfolded, its context and how the people involved in the process interpreted it and made sense of it. In addition, this type of design was best suited to the study since it allowed the researcher to “hear” the patients’ voices and thus give individuals a chance to explain their experiences in the treatment system.

3.3 GEOGRAPHICAL AREA OF THE CHOSEN RESEARCH SITE

The Stanger Regional Hospital is based in Stanger, which has been renamed KwaDukuza. Stanger is an urban area surrounded by rural areas and the hospital is situated in the Stanger Central Business District (CBD). The surrounding rural areas have clinics but no hospitals, thus many patients are referred to the hospital by these clinics (Duze 2009). The hospital falls within the geographical boundary of the ILembe District Municipality and is under the management of Ms S Dube. The researcher chose this ARV clinic in which to conduct her research as she had established that no previous research on this topic had been conducted there. Thus, there was a need to analyse the process of interactive communication between the treatment team and the individual patient in order to discover issues related to the factors that either facilitate or hamper patients’ understanding of HIV and AIDS and the correct use of ARV medication.

Another reason why this specific ARV clinic was chosen was that the researcher had previously resided in Stanger. Undertaking this study was therefore an opportunity to “give back to her community” by gauging the voices of the patients at this specific

clinic. Although the researcher is not fully fluent in isiZulu, this did not present an obstacle since a decision was made to recruit English-speaking patients only. The VCT counsellors also assisted her by translating the lectures presented during the drug literacy and ARV classes. Moreover, the researcher was provided with the documented notes used by the different medical professionals in their lectures. With the help of the counsellors and the documents provided, the researcher was able to fully understand the communication processes at the clinic.

3.4 CRITERIA FOR INCLUSION OF PARTICIPANTS

In selecting the patients, the following criteria for inclusion were used:

- The patient had to have been diagnosed as HIV-positive at the time of recruitment and must have entered the system for ARV treatment.
- The selected patients had to volunteer for participation and be willing to sign an informed consent form.
- The patient had to be willing and able to give written informed consent for the researcher to observe the communication process between him/her and each of the treatment team members and to be interviewed and for the interview to be digitally recorded
- The patient had to be an adult aged 18 years or older and able to give informed consent.

3.5 DATA COLLECTION TECHNIQUES

In-depth interviews (refer to addendum B) and observation (refer to addendum A) were the two methods selected for this study since they are key processes in qualitative methodology. The researcher's fieldwork involved analysing a patient's interaction with the various treatment team members, that is, the way in which the patient communicated and interacted with the various treatment team members during their individual or group consultations. In addition, in-depth interviews were chosen since they allowed the researcher to spend time alone with the patient and obtain their individual experiences of the interactive communication process. The

interactive communication process refers to the interaction that took place individually between the patient and each treatment team member as well as during the group lecture sessions. Thus, this refers to the communication that took place and how that communication contributed to their individual understanding of HIV and AIDS, and the correct consumption of ARV drug medication. Tenets from three different communication models were used as sensitising concepts which allowed data to be induced by the researcher as a result of the diverse nature of the medical team members that dealt with the patients. The diversity of the literature included in this study allowed the researcher to cater for a proper analysis, as well as creating an understanding of the various treatment team members and their relationships with the individual patient and vice versa. In this manner, effective understanding of provider-patient relationships could be analysed and understood. In Chapter 4, Figure 4.1 and Figure 4.2 unpack the concepts of interaction, as well as the interactive communication process as discussed above. Furthermore, the interview schedule was semi-structured which allowed the researcher the flexibility to ask more questions if patients were unable to provide a rich description of their communications with the different medical treatment team members. This flexibility was an advantage as the researcher was able to obtain many of her observations from the drug literacy classes held with the individual patients and obtain their opinions in this regard. Decisions in terms of the different data-generation methods, the sources of data and the numbers of interviewees or data-gathering sessions, as well as the reasons for these decisions, are outlined in Table 3.1 below.

Initially, the researcher wanted to observe the interactive sessions between the four recruited cases and the various treatment team members before she conducted the individual interviews. Although non-participant observation was still the first data-generation strategy in the study, the observation of a group session was initially planned for and not the observation of the patient–treatment staff member dyads.

Table 3.1: Summary of the data-generation activities

Method	Data sources	Number of interviewees/ Sessions	Justification
Non-participant observation of a group	Drug literacy workshop	A 3-day group session	To establish how patients communicate/interact with the different medical staff members To uncover/discover factors that either assist or hamper the open sharing of information
Non-participant observation of a group	Group lecture presented by pharmacy assistants	A 1-hour group session	To establish how patients communicate/interact with the pharmacy assistants To uncover/discover factors that either assist or hamper the open sharing of information
Non-participant observation of dyad	Patients with each of the following treatment team members: doctor, nurse, social worker and VCT counsellor	4 X 4 = 20 sessions observed	To explore how the patient communicates/interacts with the different medical staff members To uncover/discover which factors either assist or hamper an open sharing of information
Face-to-face interviews	Volunteer sample (4 case studies)	4 X 1 hour-long interviews	To compare and contrast the observation findings on a personal one-to-one basis in terms of the way in which the patient communicates/interacts with the different medical staff members; and which factors either assist or hamper an open sharing of information

Source: Mason (2002)

The first type of interactive communication that occurred at the clinic was the group session in the form of a drug literacy workshop hosted by the VCT counsellors and the social worker. Since the qualitative approach allowed for flexibility in the field, the researcher decided to observe the group session and jotted down notes in her research journal. The workshop occurred over a three-day period from 4 to 6 January 2010. Patients were expected to attend this three-day workshop and then return to the clinic the following week with the dates provided to them by the VCT counsellors. This was to ensure that they would attend their sessions with the different treatment team members. In this case, the patients were instructed to come back on 11 to 13 January to consult with the VCT counsellors, nurse, social worker,

pharmacist assistants and doctors before they received their ARV treatment regimen.

Interviewing the four cases prior to their interactions with the treatment team members would have inconvenienced the patients since they would then have had to travel to and from the clinic several times. Consequently, the counsellors advised the researcher to schedule individual interviews prior to “sitting in” and observing the individual patients with the treatment team members. Thus, the individual interviews occurred during the week of the drug literacy classes. The order of the data generation did not present a problem as it was still possible to test the data generated by observing the workshop attended by the various patients. Therefore, the individual interviews were held after the observation of the group session, but before the individual-and-professional (dyad) observations, which concluded the data gathering.

In hindsight, the order of data gathering proved to be of benefit for three important reasons: Firstly, the researcher was able to develop observation notes from the group session and to transcribe and analyse the individual interviews. These notes and transcriptions assisted in the final dyadic observations. Secondly, the individual interviews with the four cases helped facilitate a relationship of trust with them so that the cases felt at ease with the researcher’s presence during their interactions with the treatment team members. Thirdly, the fact that the dyadic observations occurred after the interviews (and after the first transcription of the interviews) meant that the researcher was able to follow up on issues that arose during the interviews with the four cases.

The patients informed the researcher that they were familiar with the various treatment team members since they had interacted with them when they initially entered the hospital for treatment diagnosis. The individuals had also interacted with the VCT counsellor and other treatment team members for check-ups before they embarked on ART.

The observation group session at the drug literacy classes provided the researcher with a first-hand view of what transpired during the initial stages of the

communication process as it occurred at the hospital. In contrast, the personal interviews generated perceptual data about the patients' experiences of the social process and the researcher could verify these experiences using her observations during the "sit-in" sessions between the treatment team members and the four patients. Overall, she was therefore able to analyse the interactive communication as a whole process as it occurred at the ARV clinic at Stanger Regional hospital.

3.5.1 *Non-participant observation*

Observation as a data-generation strategy occurs where researchers induce themselves into the field and look and listen attentively in order to "hear" data and absorb information. Researchers engage in the field and use all five senses to obtain naturally occurring data (Neuman 2007:287). The use of observation methods in this study was done with the aim at gathering first-hand information about a given social process (health communication directed at ART adherence) in a naturally occurring setting (a public health care facility).

3.5.1.1 *Possible limitations of non-participant observation*

The researcher conducted overt, non-participant observation; consequently, the research participants were aware of the researcher's presence and the goals of her study. This "open" position was deliberately chosen to honour the ethical requirements of the study and to help foster a relationship of trust between the research participants and the researcher.

Babbie (2008:317) points out that reactivity might occur since the participants might act differently because they are aware that they are being observed. The possible effects of reactivity were controlled using two measures. Firstly, the researcher explained the goals of her study carefully to all of the research participants. Here it was stressed that the observation was not a test or an evaluation and the participants were asked to conduct the sessions as they would normally. Secondly, the researcher bracketed all normative assumptions about "good" counselling or "good" communication so as not to bias her observations. As the researcher is a communication specialist, she thus has expert knowledge of interactive

communication techniques and practices. Nevertheless, she set aside this knowledge so that she could be open in order to interpret the observations she witnessed. The researcher analysed the data she collected from the observations and reflected on them many times before she accepted the results as final. She achieved this goal using a process of triangulation, constantly comparing and contrasting the data collected using both techniques in order to ensure that the data were valid.

3.5.1.2 *Recording observation notes*

The processes of data collection and data analysis were interwoven, thus the researcher was able to bracket her understanding of communication prior to data analysis. This worked to her advantage since she recorded her observations immediately during the “sit-in” sessions and expanded her thoughts in her notes. The keeping of detailed notes enabled reflection and the comparison of data.

3.5.1.3 *Sequencing of observation and interviews*

The first phase of observation occurred in the group sessions at the drug literacy classes from 4 to 6 January 2010, which the researcher attended. These sessions were presented by the VCT counsellors and the social worker. These sessions took place in a small room at the hospital, which had previously been used as a nurses’ tearoom. Patients were crowded into this small venue and, although chairs were provided, there were too few for all the attendees to be seated comfortably.

3.5.1.4 *Group observation*

On the first day of the group session, the researcher was introduced to the patients and she explained the core aspects of her research. She did not use the observation schedule to analyse the first group session since it was the first session she had attended at the hospital and she wanted to familiarise herself with her new research setting. The intention was to keep an open mind in inducing data according to her set research objectives, as explained in table 3.1 above. Hence, during the sessions she jotted down all her experiences, observations and thoughts in her research journal

rather than adhering to the set observation schedule. She also summarised the lectures presented by the participating treatment team members as she understood them. These notes were used later for reference during the triangulation process, when comparing and contrasting the data to ensure credibility.

3.5.1.5 *Dyadic observations*

The second phase of observation occurred between the patients and the various treatment team members, which included VCT counsellor, nurse, social worker and doctor. These sessions were scheduled for 11, 12 and 13 January. The researcher sat in on these sessions and observed the way in which interactive communication occurred. An observation schedule was used during these sessions and the researcher wrote notes on the schedule so that she could compare and contrast her notes with the transcriptions of the recorded interviews and thus triangulate her findings. On 13 January 2010, the researcher attended and observed a lecture presented to the patients by the pharmacist assistants. This session aimed at educating patients on all aspects of ART, including the correct use of medication and its side effects (see lecture notes in Appendix J).

During her initial contact with Stanger Hospital, the researcher was not informed that the lecture with the pharmacist assistants would be conducted with the group, and not individually. The researcher thus used the same observation schedule to observe the group session between the pharmacist assistants and the group of patients as with the dyadic observations; however, this did not disadvantage the data-gathering process since the core aspects of the observation schedule was still obtained.

3.5.1.6 *Development of an observation schedule*

As both group and individual sessions were observed, the observation schedule developed by the researcher and edited by her supervisor, was adapted for both. The instrument was developed, bearing in mind the goals of the study and was linked directly to analysing aspects related to interactive communication between the treatment team member and the individual patient. This is explained below with regard to the selection of specific tenets from the different communication models

were included and which are discussed in Chapter 2. Furthermore, non-verbal cues such as tone, eye-contact and language used were included to analyse how these related to the interactive communication process as it occurred between the two parties. These non-verbal cues allowed the researcher to assess whether the communication process either facilitated or hampered treatment adherence. However, the researcher realised that other non-verbal cues could evolve, that is, ones that had not been included or thought of before. Thus, the observation schedule stated that she should pay attention to other non-verbal cues that could arise during the medical professional-patient sessions. The core aspect of treatment adherence was included in the observation schedule to ensure that the researcher paid special attention to the way in which the sessions addressed this important issue with the patient. The observation schedule also catered for the inclusion of impressions about time and context. The amount of time that the medical staff spent with the patient was very important since the topic of discussion was very important; that is, ARV treatment, which was being discussed with a patient entering the medical system for treatment. Thus, various observations were related to the way the medical staff approached the patient in the given context.

Various sensitising concepts taken from the different models were included in the observation schedule. Most pertinent among these were individual *perceptions, likelihood of action, likelihood of behaviour change, and perceived susceptibility to severity of disease* (Janz & Becker 1984 in Glanz *et al* 2002:52). The following sensitising concepts taken from the KIM were included: *reaction, interaction and transaction*. These concepts assisted the researcher in analysing the interactive communication process as it occurred between the patient(s) and the treatment team members in detail (King 1971:92 in Northouse & Northouse 1985:21).

The researcher carefully observed the way in which the selected patients and medical staff interacted with each other, making notes on the observation schedule – one observation schedule per patient.

3.5.2 Face-to-face interviews

Personal interviews with the four case studies formed the second major data-generation strategy in this study. The details of this method as employed by the researcher are given below.

3.5.2.1 Setting for the interviews

The researcher conducted face-to-face interviews on 6 and 7 January 2010. Two patients were interviewed each day since this was most convenient for the patients. The interviews lasted for about one hour each on average and took place in a room located in the speech and hearing therapy clinic at the hospital. The researcher found this to be the quietest, most private place in the hospital and thus gained permission to use the room from the audiologist in charge.

3.5.2.2 Recording of the interviews

All interviews were conducted in English. Since the researcher is fluent in this language she recruited only English-speaking patients for this study. The intention was to record all interviews on a digital Dictaphone to ensure that all interviews could be transcribed verbatim. This did not, however, happen in the case of all the participants. The first interview was recorded successfully on the Dictaphone, but during the second interview it stopped recording. In order to allow the interview to flow naturally, the researcher wrote down this interviewee's answers in her journal.

A replacement Dictaphone could not be secured, so the third and fourth interviews were recorded on the researcher's cellular telephone. However, during the fourth interview the memory of the cellular telephone became exhausted, hence the second half of the interview was again recorded in the form of handwritten notes.

3.5.2.3 The interview schedule

A semi-structured interview schedule was developed to assist the researcher in gathering the information required. The semi-structured nature of this schedule

allowed for flexibility in the research, which facilitated openness and allowed the researcher to gain more in-depth information from the patient when the need arose. This schedule was created by the researcher with the help of her supervisor, who ensured that it was detailed and that most of the necessary questions were included. The tool was developed from a close review of the literature, the underlying theoretical beliefs of all the models and insights of empowerment theory. This was done purposively so that interactive communication could be effectively analysed from the researcher's perspective on a one-to-one basis. Thereafter, the researcher induced the data received and categorised it according to the specific theoretical tenet of the model into which it fitted, as will be explained in detail in chapter 4.

The KIM was used specifically to analyse the relationship between the patient and the nurse, as well as the patient and the VCT counsellor. This was done deliberately since the researcher had gathered that the VCT counsellor and the patients experienced a very close relationship, as explained by the tenets of the model. The relationship between patients and the doctor, the social worker and the pharmacist assistant respectively adhered to the theoretical explanation of the various tenets of the Therapeutic Model. Finally, the HBM data fitted into sensitising concepts such as *individual perception, modifying factors, likelihood of action, age, sex, ethnicity, personality socioeconomics, knowledge, likelihood of behaviour change, perceived threat of disease and cues to education* (Janz & Becker 1984 in Glanz *et al* 2002:52). The instrument was tested by the researcher with a colleague at work in the form of a mock interview in December 2009. The colleague was a fellow academic thus she was able to critique the researcher effectively and to give constructive advice on how to improve faults in the instrument.

3.6 ACCESS NEGOTIATION AND SAMPLING PROCEDURES

Gaining access to persons with a known HIV-positive diagnosis and recruiting volunteer interviewees from such a group proved to be challenging. The details of these steps and the ethics that guided them are discussed below.

3.6.1 Permission to conduct research at Stanger Regional Hospital

The researcher obtained full permission from the following bodies in order to conduct research at this hospital:

- the University of South Africa's (UNISA) Research Ethics Review Committee (URERC)
- Stanger Hospital's Manager, Dr AJ Mansfelder, in conjunction with the ILembe District Municipality Manager, Ms S Dube, since the hospital is geographically located within the boundary of the ILembe District Municipality.
- finally, the Department of Health of Kwa-Zulu-Natal specifically the, Provincial Health Research Committee under the leadership of Dr SSS Buthelezi.

3.6.2 Sampling procedures

For the individual interviews and the dyadic observations, purposive sampling was used to select a number of patients who attended the VCT clinic regularly. Thus, individual patients became the units of selection for this study, although the communication process was the unit of observation. According to Neuman (2007:142), *"purposive sampling is used in situations in which an expert uses judgement in selecting cases with a specific purpose in mind"*. The researcher chose this method since she wanted to recruit patients who were entering the medical system for ART. The reason for this selection was that new patients entering the hospital were systematically ordered to go to drug literacy classes and were scheduled by the hospital to visit the requested medical team (doctor, nurse, VCT counsellor, social worker and pharmacist assistant), which the researcher wished to analyse. Thus working with patients attending these sessions meant that the core aspect of interactive communication as a whole process could be analysed from the patient's perspective. Dorothy was an exception to this-- although she was a site facilitator at an ARV clinic she was entering the system again to monitor and assess her ARV drug treatment. As the researcher did not find it easy to recruit many patients who were willing to participate, Dorothy was included because she wished to 're-enter' the treatment process and obtain new information in order to remain adherent to her ARVs. The VCT counsellors assisted the researcher to recruit the

four participants for the study, hence adhering to the purposive sampling method for patient recruitment.

Hospital management allowed the researcher to introduce herself on the first day of the drug literacy workshop on 4 January 2010. At this workshop she explained the goals of her study to the group of patients and recruited five patients, of which only three took part in the study. The interviews took place on 6 and 7 January 2010. The VCT counsellors assisted the researcher greatly in recruiting a further patient who was fluent in English and willing to participate in the research. The VCT counsellors had been provided with the selection criteria for patient participation in this study prior to these classes when the researcher visited the hospital in December 2009 to meet with the VCT site mentor to discuss her study.

After the first workshop on 6 January 2010, the VCT counsellors provided the researcher with the dates on which the patients who had been selected for the study were to return to the clinic for scheduled sessions with the various treatment team members. This sampling method worked to the researcher's advantage since owing to issues of stigmatisation and the fact that the researcher was regarded as an outsider it would have been difficult to recruit participants for the study without the counsellor's intervention. These aspects will be discussed in greater detail later in the chapter.

The inherent nature of this study did not demand a large sample size, but rather depth and richness in the data that were gathered, which was achievable using this small and convenient sample size. Although the sample was small the researcher makes no claims to representativeness, because the research goal was to gain "understanding" of the interactive communication process rather than to generalise the findings to the entire patient community at the ARV clinic.

3.7 DATA ANALYSIS AND INTERPRETATION

A thematic analysis was used to interpret and organise the data collected for this study. This analysis enabled the researcher to sort out the data by grouping similar ideas and information provided by the patients together into similar stories indicating

different ideas or thoughts (Overcash 2003:183). As the researcher immersed herself in the fieldwork, she induced data according to the sensitising concepts she had obtained from the literature survey, as explained above. Various themes that emerged from the study linked up well with the literature reviewed in Chapter 2. These themes are explained in Chapter 4. The process of data gathering and data analysis became interwoven in the study, thus adhering to the emergent design. Data were analysed in an *interthematic* manner according to which themes were compared among the different case studies and thus similar narratives emerged and consequently information became structured in this form (Overcash 2003:183).

The researcher used two data collection methods, namely observation and individual interviews. During the course of these, she noticed that various themes that evolved overlapped and were interdependent of other themes that had evolved. On completion of each interview, the researcher transcribed the recordings immediately and compared what had been recorded to her written notes and combined the information received from both methods. In cases where she was only able to write down the interviews due to the failure of the recording devices, she worked with her detailed notes.

Individual patient responses were recorded in a journal as case study 1, 2, 3 and 4. This allowed the researcher to organise data per case study. Observation notes were recorded on an observation sheet and were then compared with the transcriptions formulated for each case study. Within a theme sub-themes were created from the data collected. The researcher constantly compared the interview transcriptions with the observation notes to check for accuracy in the data received. The process of combining data gathering with data analysis worked well, as the researcher was able to link that which she induced in the field immediately to the sensitising concepts that emerged from the literature.

3.8 ISSUES OF RELIABILITY AND VALIDITY

The researcher engaged in multiple methods of data collection, namely, non-participant observation and in-depth interviews. Thus she was able to produce valid and diverse viewpoints of reality as they occurred.

Morse, Barret, Mayan, Olson and Spiers (2002:10–13) suggest five strategies for verifying the authenticity of data in qualitative research, namely:

1. ensuring methodological coherence
2. striving for sampling sufficiency
3. developing a dynamic relationship between sampling, data collection and analysis
4. thinking theoretically
5. developing theory

The researcher adhered to the first four strategies by, firstly, ensuring methodological coherence in the congruence between the research question and the research design as detailed in this chapter. Secondly, the criterion for sampling sufficiency demanded that she recruit and select participants who best represented the inclusion criteria or were likely to have knowledge of the research topic. Thirdly, the criterion for developing a dynamic relationship between sampling, data collection and analysis demanded that the processes of data collection be combined with data analysis. In this regard, the selected qualitative research design allowed for flexibility and concurrent data collection, note taking, transcription and analysis throughout the fieldwork period. Moreover, it allowed the researcher to make adjustments to the interview and observation schedules when unusual findings in the field so required. Finally, the researcher enhanced the credibility of her data by thinking theoretically so that emergent ideas were tested against the literature reviewed. For this purpose, the researcher wrote notes in her research journal to enable constant comparison, checking and reflection.

3.9 ETHICAL CONSIDERATIONS

The researcher is a qualified lay counsellor and was thus familiar with the ethical requirements for maintaining confidentiality in a clinical setting. In addition, she was guided by UNISA's policy for ethical research conduct and thus adhered to the principles of confidentiality, informed consent and debriefing as detailed below.

3.9.1 Confidentiality

The researcher maintained her moral obligation to her research participants by protecting their identities. The true names of the recruited participants are only known to the researcher and the VCT counsellor and these details were noted in the research journal which is kept under lock and key. The researcher personally transcribed all her interviews and thus the participants' actual names were edited out in order to protect the participants' identities. During the analysis of the data, pseudonyms were given to each participant. In addition, the names of the treatment team members were kept private and are not divulged in the dissertation.

3.9.2 Informed consent

Although the participants were purposively selected, participation in this study was completely voluntary. Participants had a choice in whether to be part of this study and could withdraw from it at any stage without any penalties. They were provided with informed consent forms in which they were informed about the study and asked to sign to indicate their consent to their participation. Verbal consent for the researcher to sit in with the patients during the observation sessions was obtained from the treatment team members at the ARV clinic.

3.9.3 Debriefing

The research was conducted in a clinical setting, thus the researcher was in a suitable position to refer the participants back to professional medical staff had problems occurred. However, the research conducted was not invasive research thus no problems occurred during the data collection. The researcher also provided the patients with her full name and contact numbers in case they wished to contact her for further information after the study was completed.

3.10 REFLECTION ON THE INFORMATION-GATHERING PHASE

As befitted a qualitative orientation, the researcher made notes in her research journal concerning the methodological decisions taken, her conduct as a researcher and her emic and etic roles. These issues are discussed below:

3.10.1 Recruitment of volunteers for the interviews and individual observations

It was difficult to recruit volunteers for the face-to-face interviews even with the assistance of the VCT counsellors. Many of the patients approached to participate in the study refused to do so, citing as reasons their difficulty in dealing with their feelings of being stigmatised. In addition, as explained below, the patients saw the researcher as an outsider and thus shied away from confiding in her. However, the unit of observation in this study was the communication interaction between the patient and each member of the treatment team – thus a large number of volunteers were not required since the intention was to understand the communication process.

Initially five patients volunteered to participate in the study. However, only three of these eventually took part in the face-to-face interviews. The two who dropped out included a woman whom the researcher could not locate as she did not return to the classes, and another woman who collected ARV medication on behalf of her child, and thus did not meet the inclusion criteria. Eventually, with the help of the VCT counsellors, a fourth case study was recruited – a male Zimbabwean who met the selection criteria. Language did present a major obstacle in the interviews as only English-speaking patients were recruited. However, the VCT counsellors facilitated matters by translating the literacy class lectures for the researcher.

3.10.2 The observation phase: data gathering and data generation

The units of observation for data generation were the clinic (to observe what a typical day at the clinic entailed), the literacy classes and the interviews blended with observations of the interaction between the four patients and the members of the treatment teams. In respect of the four case studies, the researcher conducted

individual interviews with each of them and sat in as an observer on the various sessions with individual members of the treatment team.

The individual interviews with each of the four volunteers were conducted alone in a private room at the hospital behind closed doors. However, the observations between the social worker, nurse and counsellor and the patients were conducted in various spaces in the clinic. The arrangement at the clinic was that these staff members operated from the same room but were seated at different desks. Each patient's session with the doctor took place in a private consulting room, whereas the session with the pharmacist assistant occurred in a group setting. As befits naturalistic enquiry, the researcher observed these interactions (communications between the patients and the treatment team members) in the actual locations in which they normally occurred.

3.10.3 Considering the emic and etic roles of the researcher

The researcher recorded all her observations, impressions and discussions in a research journal, which allowed her to reflect on the data-gathering and data-analysis processes. She tried to immerse herself in the field of the ARV clinical setting and interacted with the HIV-positive patients; however, throughout the research, she was regarded by the patients as an outsider. Although she tried to blend into the data-generating setting by sitting in class with the patients and listening to lectures with them, she never managed to shake off her outsider status. In addition, she spent the entire day at the clinic and interacted with the treatment staff, she smiled and tried to befriend the patients, but to no avail. Unlike the treatment staff, she was never regarded as a "familiar face". These perceptions were confirmed in a discussion with the senior nurse at the ARV clinic, who commented: *"The patients do not trust you at the clinic since they consider you as an outsider to them, they do not see you at the clinic therefore they shy away from you."* The researcher thus became familiar with the clinic and, as a result, regarded herself as an insider in the data-gathering phases; however, her status as an outsider in the patients' eyes allowed her to maintain her objectivity throughout the data-gathering phase

3.11 TRIANGULATION OF DATA

Triangulation is a process that includes more than one method of data collection. According to Patton (1999:1193) four types of triangulation contribute to verifying and validating qualitative data:

1. methods triangulation
2. triangulation of sources
3. analyst triangulation
4. theory/perspective triangulation

The researcher used *methods triangulation* and *theory/perspective triangulation* to validate her findings. In terms of *methods triangulation*, two different methods for data collection were used which enabled the researcher to verify the data obtained from the transcriptions with those obtained from the observations. In terms of *theory triangulation*, the researcher conducted a comprehensive literature review which encompassed multiple theoretical models. These models yielded sensitising concepts that were used in the interpretation of the data.

3.12 CONCLUSION

This chapter introduced the methodology chosen for the study. The justification for the qualitative research methodology selected was outlined, since this study aimed at understanding patient care and not predicting it, consequently adhering to the interpretivist paradigm selected. Detailed information was provided on the data-collection techniques selected for the study, the sampling methods, the data analysis and interpretation methods, as well as issues related to ensuring that the data collected were reliable and valid. Ethical issues were also reported on with explanations as to how they were overcome. The next chapter provides a detailed explanation of the findings of the study.

CHAPTER 4: ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

In this chapter, the researcher presents the findings of the study. These are grouped according to the themes and sub-themes that emerged from the analysis of the data. In large part, the sequencing of the discussion of the findings was influenced by the objectives of the study, that is, the order of the data-generation steps and the structure of the data as revealed in the analysis of the observational notes and the transcribed interviews.

The first section of this chapter comprises of a discussion of the clinic structure and a detailed account of the procedures typically followed by HIV-positive patients upon entering the treatment care phase at the Stanger Regional hospital. The individual case studies are introduced and thereafter the major themes and sub-themes are discussed as they emerged. Different forms of communication, as observed at the ARV clinic, are discussed in turn, that is, the drug literacy workshops and communication sessions offered by the different members of the medical team. A detailed discussion is provided of the interactive communication process explaining how each treatment team member (doctor, nurse, social worker, VCT counsellor and pharmacist assistant) acted in terms of either facilitating or hampering the patients' understanding of HIV and AIDS and ART.

4.2 CLINIC STRUCTURE

The information for this section was gathered by means of observation and from discussions with a nurse based at the clinic. The ARV clinic at Stanger regional hospital treats on average 100 patients daily with limited human resources. Research has indicated that, in South Africa, the KwaZulu-Natal province in particular suffers from health care staff shortages (Deghaye, Pawinski & Desmond 2006). People at the lower income levels rely solely on the public health care system for treatment and care; hence, the treatment system is overburdened and cannot cope (Ransom & Johnson 2009:48–49).

At the time of data gathering, there were seven nurses at the clinic, five of whom attended to ARV patients whilst the other two assisted paediatric patients. There were two medical doctors at the clinic; one of whom attended to adult patients and the other to paediatric patients. Two administrative clerks assisted with the paperwork and record keeping. The clinic had three VCT counsellors. In addition, five pharmacist assistants based at the clinic, educated patients and provided ARVs. One of these assistants was in charge and guided and supervised the other four. In addition, two of the assistants offered services at clinics in the areas surrounding Stanger, such as Glen Hills, Billiton, Darnell, Chakaskraal and Phumelelo.

4.3 TYPICAL CLINIC PROCEDURES

A typical day at the clinic would start around 08:00, although patients are requested to arrive at 07:00. The nurses attend to patients individually by performing basic medical assessments such as weighing them, taking their blood pressure (BPs) and measuring their height. When requested, blood tests are performed and patients are referred for X-rays. Pregnancy tests are performed on female patients. While patients await their test results they are sent to the social worker for psychosocial testing. Once all the test results are available, the patient is referred to the VCT counsellor to complete a "clinical chart". This is a document in which the nurse and the VCT counsellor record the patient's physical and social conditions and treatment history. Finally, the patient is sent to the doctor who reviews the clinical chart and, if satisfied with the patient's progress, he or she approves ARVs for the patient. This entire process takes under half an hour per patient; usually each treatment team member spends on average five minutes with each patient when completing the various forms. In addition, after the drug literacy workshop in the second week, the patients are provided with a schedule of dates for their consultations.

The researcher observed how patients have to wait in long queues. Although the sessions are rushed, in most cases patients usually spend the entire day at the hospital. A comprehensive assessment is made in one place (the ARV clinic) where patients work closely with the treatment team. However, the counsellors and the nurses perform most of the assessments and thus it has been observed that patients seemed most comfortable in communicating with these staff members.

4.4 BACKGROUND ON THE CASE STUDY PARTICIPANTS

A brief summary of each participant's biographical information is provided below. Pseudonyms were used for each of the four participants in order to protect their true identities.

4.4.1 Solly

Solly was born in Zimbabwe but migrated to South Africa in search of a better life. He explained that he had had many family responsibilities and was the sole breadwinner. He worked in the construction industry. At 29 years of age, Solly was the youngest participant.

4.4.2 Samuel

Samuel was the first person to agree to participate in the study. He was 42 years old, a married man and a father of young children. In his interview, he stressed the importance of cultural factors in ART.

4.4.3 Hula

Hula and Samuel are husband and wife. Hula was also 42 years old. She quoted her reason for volunteering to be part of the study as her strong conviction that ARVs will make her healthier to *"live a long, healthy life with my family, children and friends"*. In her interviews she presented herself as a deeply religious person who is kind-hearted, who perseveres and prefers to focus on the positive. She knew that she could not be cured, but felt convinced that she would be able to live a healthy, happy life with the help of ARVs.

4.4.4 Dorothy

Dorothy was 42 years old, and a site facilitator at an ARV clinic. She presented herself as a positive person who was enthusiastic to participate in the study. Dorothy

described herself as someone who believes in helping others. She was diagnosed as HIV positive in March 2006, but has enjoyed reasonable health since she has been adherent to her ARVs.

4.5 EMERGENT THEMES FROM THE DATA COLLECTED

This section outlines the major themes and sub-themes that emerged from a data analysis of the various observational notes and individual interview transcriptions.

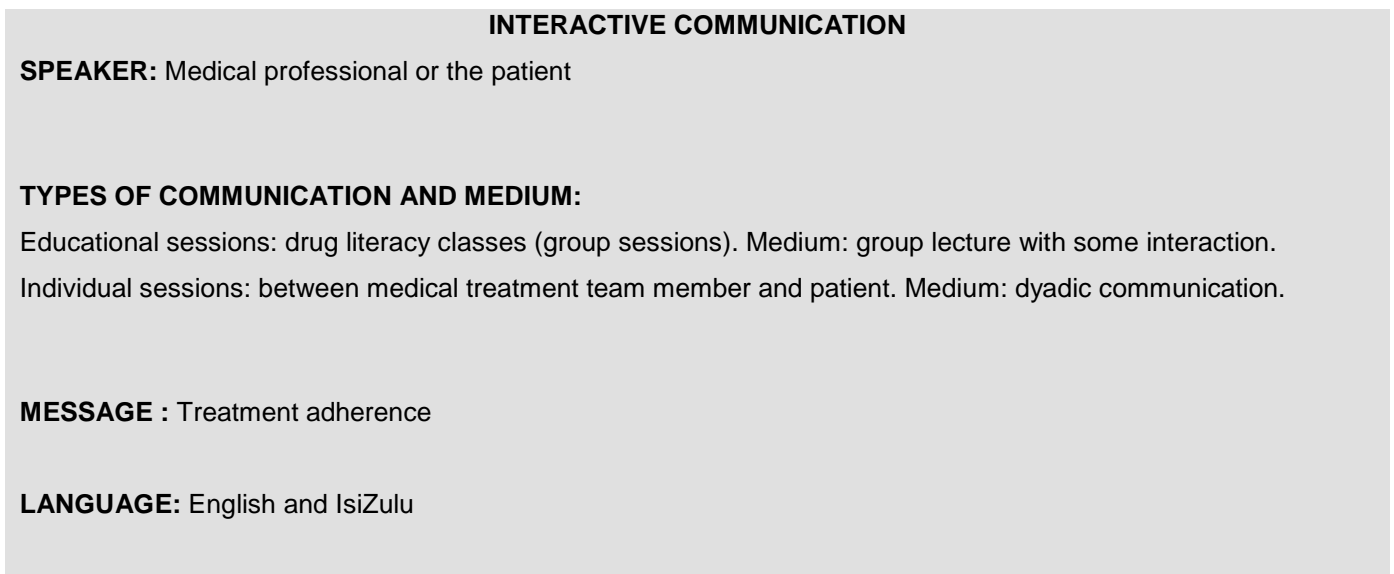


Figure 4.1: The process of interactive communication as observed in the study setting

Figure 4.1 displays the different forms of communication that occurred at Stanger hospital. The major theme included interactive communication by the speaker (either the medical professional or the patient), the reason for the interactive communication (which in this case refers to education on ART adherence provided by the medical professional) and finally, the language the message is conveyed in, which was either English or isiZulu.

4.5.1 The drug literacy class workshop: patient education and building a relationship of trust with the treatment team

INTERACTIVE COMMUNICATION IN THE DRUG LITERACY WORKSHOP

MESSAGE: HIV AND AIDS & ARV DRUG ADHERENCE

COMMUNICATORS: VCT COUNSELLORS & SOCIAL WORKER

TARGET: HIV POSITIVE PATIENTS' REFERRED TO CLASS

Figure 4.2: The communication process at the drug literacy classes

The Stanger hospital hosts scheduled educational workshops which are called drug literacy classes. These are held with patients who are diagnosed as HIV-positive and who have entered the ART stage of their illness. These classes are held to educate and empower them about ART, and HIV and AIDS in general. This is the first type of interactive communication that occurred between the patients and the medical staff during the fieldwork phase.

The VCT counsellors were the main educators during these scheduled sessions. The classes were hosted over a three-day period, covering different modules each day. The modules included lectures on stigma, disclosure, positive living, HIV care and treatment, the different types of ARV available, drug regimens, adherence, side effects, resistance and finally the treatment plan (National Department of Health-KZN [sn] – see lecture notes, Drug Literacy class workshop, Appendix H). These educational sessions complement the recommendation by Mcquiston, Choi-Hevel and Clawson (2001:278) that *“key to the empowerment approach is the recognition that individual and interpersonal thoughts, feelings, and actions are embedded in and interactive with the social, economic, and political context in which people live”*. Salmon and Hall (2004:54) comment that, *“by learning such skills, patients are regarded as changing from sufferers from their disease into managers of it”*. These authors (Salmon & Hall 2004:54) also note that language is important, since patients need to understand the communicated messages in order for these classes to be effective in transferring knowledge. The entire workshop at the hospital was hosted

in isiZulu. This was effective as a communication medium as the hospital is based in KwaZulu-Natal where isiZulu is the dominant African language spoken.

The drug literacy class process at the hospital educates patients who thus become empowered. These classes supply methods of training and support that aim to teach patients how to cope with their disease and to take ARVs effectively (Lau 2002:373; Marelich, Roberts, Murphy & Calare 2002:24).

The researcher acted as a non-participant observer in these educational sessions. Three VCT counsellors led the lecture series and educated a roomful of 36 adult HIV-positive patients of both genders and various ages. In the first session, the researcher was given a chance to introduce herself and explain the core aspects of her research.

During the social worker's session, on day 1 of the drug literacy classes, some of the topics already discussed by the VCT counsellor were reiterated, such as positive living, the use of social grants and adherence to ARVs. She placed much emphasis on support and disclosure to help an individual cope with his or her disease. This session was interactive and informal and it was observed that the topic of social grants elicited much interest from the group. The patients asked questions about the amount received, eligibility for a state grant and the procedures for obtaining it. The VCT counsellor confided in the researcher that in the past, patients used to default on treatment in order to receive the social grants because in the absence of ART, their CD4 counts would dip below 200 (which qualified them for a grant). However, this dangerous practice no longer exists as the doctors could declare patients eligible for the grant by taking other factors besides the blood tests into account (Observational notes, Field journal entry for 4 January 2010).

During the first week, three days were spent on lectures concerning the basic facts of HIV and AIDS as a disease. This was followed by lectures on ARVs, adherence therapy and the possible side effects that could result from taking the medication. This information was given as simple, direct facts. Some patients turned it into interactive communication by asking questions pertaining to the ARVs.

As the week progressed, many more patients joined the classes, thus the venue became overcrowded and space became a problem. Some patients had to stand as there were not enough chairs. This situation led to less interaction between the patients and the VCT counsellors. Patients looked uncomfortable and seemed to eagerly await the end of the session. Such a situation is an example of a possible communication barrier for patients since they seemed to lose interest in the information provided to them as a result of the overcrowded conditions. The researcher observed that some of the attendees were visibly unwell which clearly exacerbated their discomfort and probably added to their losing interest (Observational notes, Field journal entries for 5- 6 January 2010).

Reflecting on this observational data gathering, the theme that stood out was that of patient education. Linking back to the empowerment theoretical framework, as outlined in chapter 2, the kind of education provided in these sessions empowered the patient by gaining knowledge of their illness. All of the patients who attended the classes were educated in a very basic, yet informative manner about HIV and AIDS. By linking these observational notes to the interviews, it emerged that each of the four patients had come to the conclusion that the VCT counsellor provided them with the most effective communication. The researcher also observed that during the drug literacy classes, the VCT counsellors were the members of the treatment staff who spent the most amount of time with the patients. The confidence the patients had in terms of the counsellors was further confirmed in the findings from the interviews. For example, Hula, Samuel and Sully did not seek outside educational information on AIDS, but instead relied solely on the information they obtained from the counsellors in the lectures. Dorothy had additional information since she was an ARV site facilitator at Darnell clinic and thus had access to informative and educational material.

Hula commented: *“The VCT counsellors will relax if they speak to you, they do not rush, they tell you to ask questions, they laugh ...”* Samuel explained that the VCT counsellors were most helpful to him in terms of accessing information and he proclaimed: *“I fully understand how to take ARVs.”* Samuel also mentioned that due to the education he had received on AIDS and ARVs, he no longer felt afraid or ignorant and therefore too intimidated to ask questions related to his treatment. He

explained: *“I was not educated about it ... after I received education on the disease I did not feel shy to ask about it!”*

Dorothy explained that the entire treatment team assisted her to become knowledgeable about her disease. In contrast, Sully, Hula and Samuel believed that the VCT counsellor provided them with the most useful information. Sully observed: *“We take a long time with them, today repeating the same thing, VCT counsellors are most important to me.”*

Sub-themes that emerged in the theme of patient education were mutual trust and respect. In each of the interviews with the four volunteers, this theme of mutual trust and respect between the VCT counsellors and the patients emerged. The patients all expressed the utmost respect for the VCT counsellors and referred to them as their best educators.

This finding was further supported by the researcher’s observations during her “sit-in” sessions with the four patients and the VCT counsellors. These counsellors displayed obvious overtones of friendliness and caring in their interactions with these four patients. Moreover, each of the case study volunteers seemed to have established a relationship of trust with the counsellors. The non-verbal cues the researcher observed during these interactions further justified the observation that the VCT counsellors were kind, compassionate and very welcoming to the patient. Although they attended to many patients, they still took the time to smile and greet the patients, talk to them, and lighten the tense atmosphere by sharing jokes with the patients. The one aspect that stood out for the researcher was that of equality created by the VCT counsellors with the patients. They sat with the HIV-infected patients and related to them as they would relate to a friend.

This relationship between VCT counsellors and the patients can be viewed in terms of the theoretical framework of the HBM. The counsellor provides interactive communication for the patient that is information-driven, care-driven and instructive on how to live as an HIV-positive person (and thus the communication is also person-driven). The counsellors attempt to change the individual perceptions of the patient and to educate them on how they can live with their disease (Jan *et al*

2002:52). This provider–patient relationship clearly displays the way interactive communication facilitated each case study’s understanding of HIV and AIDS and the use of ARVs. It also provides answers to the second research question of this study. Communication that occurred between the patient and the VCT counsellor was very effective since it contributed positively to the treatment provided at the ARV clinic. This open relationship displayed trust and respect which contributed to an open sharing of information between the patient and the VCT counsellor.

Although much of the sessions with the counsellors were devoted to completing forms, the counsellors nevertheless took time to build relationships with the patients as indicated above. As suggested by Adler and Adler (1987), observational data-generation strategies may elicit altered practice or the so-called Hawthorne effect. However, the researcher spent extended amounts of time in the clinic setting and cross-checked the impressions she had formed of the conduct of the counsellors in her face-to-face interviews. The aspect of adherence was always emphasised in the time that each counsellor spent with each case study (Observational notes, 13 January 2010).

The KIM emphasises the relationship between the counsellor and the patient as a core activity for establishing effective health care. In terms of this research, an interpersonal relationship emerged between the two parties during which a *transaction* occurs, with the goal of adherence to ARVs. The sensitising concepts of *action* and *reaction* were analysed with regard to the non-verbal cues the researcher noted in the hosted session. As discussed above, these non-verbal cues (a smile when greeting the patient, talking kindly and compassionately to the patient in an appropriate tone, sharing jokes with the patient in order to lighten the atmosphere) facilitated effective communication between the two parties. The patients perceived the counsellors as effective communicators in contributing to their positive health since their compassionate actions assisted the patients to judge their new health condition more effectively (Northouse & Northouse 1895:20).

4.5.2 Interactive communication with the treatment team

As mentioned above, the central theme that flowed throughout the research process dealt with interactive communication and its impact in terms of either facilitating or hampering a patient’s understanding of HIV, AIDS and ART. The next section provides a description of how each treatment team member, namely, the doctor, nurse, VCT counsellor; social worker and pharmacist assistant, assisted the individual case studies in achieving this goal.

MESSAGE	COMMUNICATOR	COMMUNICATED TO TARGET
Role-player educates patient in the drug literacy class via lecturers Role-player emphasises ARV adherence Role-player performs routine check-ups on HIV-positive patient	Role-players Doctor Nurse VCT counsellor Social worker Pharmacist assistant	Patients (either during individual sessions or group sessions at the literacy classes)

Figure 4.3: Summary of findings regarding communication with the treatment team

4.5.2.1 Communication with the medical doctors: power differentials and time constraints

From the face-to-face interviews conducted with the four patients, it emerged that all of them were pleased with the services provided to them by the doctor. In this regard, they all emphasised how the doctors reassured them that their disease was manageable. For example Hula said: *“The doctor was very nice, I can live, I mustn’t be scared of AIDS, it’s just like any other TB [tuberculosis], sugar [diabetes], and I can live”*.

According to Samuel, *“he was very good, my doctor explained very well to me after she saw my result ... this disease is the same like flu, out of ten people in the street nine are infected”*. Dorothy recounted how her relationship with the doctor was characterised by *“good communication, since I started [in] 2006 [with] ARVs [in]*

March 29, no problems [smiling] ... still continuing, I am sticking to it!" [Her smile was analysed as a non-verbal cue which indicated how proud she was of herself for having achieved her adherence to ARVs.] Solly explained how the doctor was, *"lecturing me on how to use the tablets ... lucky it was in English, communication and socialisation was 100%"*.

These findings were, however, not supported by the researcher's own observations when these patients interacted with the medical doctor. It was observed that in the sessions with the doctor each of the four patients took on a subservient demeanour. They tended to become quiet and withdrawn. They were observably less talkative and active in the presence of the doctor than in any of their other sessions. This was exacerbated by the fact that the sessions with the doctors tended to be rushed affairs owing to time constraints. No development of rapport was observed during these sessions, which the doctors led. There was little eye contact and the doctors focused on completing the necessary forms. The entire session tended to be overshadowed by the assessment of the patient's readiness to embark on ART (Observational notes, 13 January 2010).

The analysis of the observational and interview data pertaining to the communication between the doctors and the patients revealed that there were power differentials that could be regarded as giving rise to organisational and cultural "noise" that hampered the exchange of information. The doctors tended to adhere to a biomedical model of treatment and care in terms of which the medical doctor is seen as the expert who possesses medical knowledge and thus knows best. It was observed how the superior role of the doctor was maintained throughout the individual sessions with the patients. For example, the doctors were very direct in their speech and ensured that they controlled the way the short session proceeded. Their main aim was to complete the necessary forms, assess parts of the clinical chart that had already been partially completed by others in the treatment team and finally assess whether the patient was ready to begin ART. A discussion is provided below on Hula's interaction with the doctor and how superiority (with regard to visible power differentials) was observed during her session with the doctor. (Observational notes, 13 January).

In analysing this, the concept of *perceived benefits* from the HBM is useful. Since both parties seemed to have agreed that the doctor always knew best with regard to patient treatment and care, little discussion took place. Instead, when patients raised their concerns about symptoms, the doctors tended to brush them off and prescribe medication instead of giving the patient a thorough explanation for their condition. According to the concept of perceived benefits, the doctor should provide an explanation that would ease the patients' perception of the diagnosed treatment (Janz *et al* 2002:49). However, this was not done and this ineffective communication caused the patients to experience psychological and semantic noise since they were discouraged from acting as free agents in the treatment system. The doctors' use of superiority in their tone affected the patients psychologically.

Patients were not given a chance to ask questions regarding their treatment nor were they able to raise any concerns. The doctor did most of the talking, and when the issue of adherence was broached, each patient agreed subserviently to adhere to their ARV regimen. Solly and Samuel were the only patients who raised concerns about their health: Solly had a rash that concerned him greatly while Samuel had swollen glands in his neck area that worried him. It was observed that the doctors allowed them time to voice their concerns, but then merely prescribed medication for these symptoms.

Changes in Hula's body language and demeanour were particularly obvious and patently demonstrated her subservience in the presence of the doctor. She sat very quietly throughout the session, her hands clenched tightly, looking at the doctor and agreeing to be adherent to her ARV treatment. The researcher concluded from these non-verbal cues that she was afraid of the doctor and thus listened more than she spoke.

Since Dorothy was already taking ARVs, her session dealt with monitoring and assessing her ART. The session was also rushed, although she had to adjust to a new doctor since her regular doctor had resigned. The doctor asked her questions to gain clarity about her treatment thus far and told her to continue adhering to her ARVs (Observational notes, 13 January).

During the face-to-face interviews the theme of power differentials emerged, but only because of prompting by the researcher and it was never mentioned spontaneously. Hula clung to her belief that the doctor knows best and is superior to the patient and to other members of the treatment team. For example, when she was asked whom she would consult about her ART regime she commented, *"I can ask the doctors, because they know more, the nurses refer questions to the doctor, I am not afraid of the doctor"*.

As explained earlier, this last statement was negated by her apprehensive reaction to the doctor during the observational sessions. Hula (like the other three respondents) was dependent on the public health care system for her treatment. Her reaction to the doctor and her reverence for the doctor's position probably stemmed from her dependence on this service. Hula felt safe in expressing her dislike for the assistant because of what she perceived as being poor communication skills. She commented: *"He doesn't know more about human life, everything he knows he gets from the doctor, he doesn't know more than the doctor."* When she was asked who she would confide in if she ever defaulted, she said, *"I can tell the doctor because the counsellor doesn't know more about medication, what will happen to me if I forget ARVs, the doctor knows more about ARVs, I feel comfortable to speak to them [she is referring to the VCT counsellors] but they don't know more about ARVs unlike the doctor"*.

Samuel expressed a different attitude towards the doctor as part of the treatment team. When he was asked which member of the treatment team provided him with the most helpful information related to ARVs, he commented: *"I fully understand how to take ARVs. The VCT counsellor is better than the doctor, because the doctor taught me about CD4 counts, but gave no real reason for why to take those (ARVs)."* He acknowledged that it was difficult to communicate with the doctor, as he explained: *"Yeah, but with this doctor it's not easy, questions"* [He meant that it was not easy to ask the doctor questions]. Samuel explained how he was diagnosed with tuberculosis (TB), but only after switching to a different doctor. He experienced this as ineffective communication, since the first doctor consulted did not explain the co-infection between HIV and TB to him and he thus had to resolve the problem on his own by seeking help from another doctor.

Dorothy explained how the doctor did not educate her about her condition, but merely treated her when she had a medical problem. This treatment-focused communication became an issue for Dorothy when she experienced side effects whilst following a particular regimen. The doctor helped her by changing the drugs she was taking, did not teach her about possible side effects or explain why the new drugs had been prescribed. Despite this, Dorothy shared Hula's belief that the doctor is the most knowledgeable person with the most power in the treatment team. She commented: *"there is only one person who instructs you to stop taking meds, no one stop meds, only the doctor"*.

Solly also experienced his communication with the doctor as one-sided and explained: *"The doctor didn't ask me anything, only wrote one question, full stop"*. This was supported by the researcher's observation that the doctor spent very little time with Solly. No real trust or care was built up with the patients in this rushed session (Observational notes, 13 January 2010). Solly, like Hula and Dorothy, believed that the doctor was the most knowledgeable and superior member of the treatment team since he stated that he would go to the doctor for help if he defaulted since he was the only person who could help him. He commented: *"I will come straight to the doctor, I won't be quiet, I will tell the doctor so that he can make arrangements to make the tablet work for me, if I stay quiet it will be a problem"*.

According to Northouse and Northouse (1985:19), if medical professionals maintain their superior position during the treatment and care of patients, these *modifying factors* contribute to ineffective care and treatment of the individual. The formality of the doctor towards the patient had a hampering effect on treatment care and the lack of interactive communication contributed negatively to patients' understanding of HIV, AIDS and ARVs. This controlling position resulted in the patients acting in a subservient manner towards the doctor.

One issue that further dominated the doctor–patient communication was the organisational "noise" in the form of the **lack of time** in the public health care system and the **lack of privacy**. As a result of time constraints, medical professionals rush the patients; treatment team members spent less than five minutes with each of the

patients (Observational notes, 11–13 January 2010). Other interactions are intended to make up for this, so that the drug literacy class sessions extend until midday over the three days and the group sessions with the pharmacy assistants extend until midday too. The drug literacy classes are not private sessions; in fact, privacy does not feature much in the public health care system.

The four interviewees experienced this organisational noise in different ways. Samuel felt that many HIV-positive people do not come forward for treatment at the clinic because of privacy issues. He commented in this regard, *“people are affected but afraid to come front because of the procedure, privacy must mean privacy! Some people run away and die because they in the class for ARVs therefore positive”*. He felt that the lack of privacy hampered effective communication and also caused patients to experience psychological noise due to stigmatisation. It has already been observed that during the literacy classes the venue was overcrowded. Moreover, everyone present knew that the attendees in that venue were probably HIV-positive. Since HIV and AIDS are still stigmatised, the patients tended to prefer the privacy offered by the treatment sessions (Observational notes, 4 January 2010). When Samuel was questioned about recommendations for improvements at the clinic in future he was the only patient who mentioned that privacy and respect for patients’ rights should be addressed. He also brought up the issue of time as being a barrier to effective communication as a result of staff overload. Samuel said: *“Members of literacy class team must be increased [he used hand actions to illustrate the urgent need for more staff members] people that are affected are more than the team, the team is overloaded”*.

Dorothy mentioned in her interview, that *“they are very busy”*. She was referring in this regard to the entire treatment team (Observational notes, 11 January 2010).

4.5.2.2 *Communication between patients and nurses: patient-centred communication*

Each of the four patients had commented positively on their relationships with the nurses at the clinic. Overall, they seemed to have engaged more with the nurses and to have communicated their concerns more openly with the nurse as compared to

the doctor. The patients were asked to describe the role played by the nurse in helping them to understand how to use and adhere to their particular ART regimen. Hula reiterated how the nurse had emphasised the importance of treatment adherence to her. She commented: *“She [the nurse] explained like the doctor [that] there are some side effects but do not stop, come back to the doctor, he will change me [she meant that if side effects were experienced he would change her regimen]. [The nurse] emphasised that I mustn’t stop ARVs.”*

Dorothy also explained that the nurse had helped her to understand her medication. She maintained strong eye contact while she expressed herself as follows: *“Only if you forget tablet names they help you, weigh us; take BPs [blood pressure] only the nurse can send you back to the doctor or referral.”* She stated that the nurses decide either to prescribe antibiotics or to refer the patient back to the doctor.

Solly felt that the nurse understood him well since he was able to speak to her and thus felt that in this way he got many of his questions regarding his treatment and disease answered. He commented: *“She repeats the same thing and we were asking questions, manage to understand us, nurse plays a big role”.*

The HBM tenet of *perceived benefits* supports these views of the research participants. The nurse was able to communicate the benefits of ARVs and the importance of adherence to each case study successfully, as explained above (Janz *et al* 2002:49).

The researcher specifically asked the patients to describe the role played by the nurse in helping them to understand how to live with their disease. Hula recounted how the nurses educated her concerning safer sex, and how to disclose her condition to a close family member, the nurse also assured her that her family would stand by her. Samuel had similar positive comments and commented that he raised his concerns about the swollen glands and TB with the nurse since the doctor barely assisted him. Dorothy expressed her relationship with the nurses as *“very fine, they understood us very well”*. Solly (like Samuel) raised his concern about a rash on his arm with the nurse. She reassured him and he commented: *“She explains to me how it goes away”*.

The concept of *perceived severity/perceived threat* from the HBM can be used to analyse patients' concerns about the social consequences of disclosing their HIV status. The nurses helped Hula understand how she could practise safer sex, and still maintain family relations even though she was HIV-positive. Samuel and Solly were give reassurance and advice on overcoming their medical condition. Thus, their *individual perceptions* of their new illness were altered positively (Janz *et al* 2002:48).

This nurse–patient relationship, as explained by the various patients, was supported by the researcher's observations. The nurses were observed over the course of the fieldwork as actively engaging with all of the patients in a friendly, welcoming and caring way. The nurses took time to speak to the patients and to assist them with the problems and concerns they raised, although the sessions with the nurses were also aimed at completing forms. The nurses constantly brought up and readdressed the issue of treatment adherence with the patient. The non-verbal cues observed during the treatment sessions were analysed as friendly. The nurses used a welcoming tone of voice when they spoke to each patient. The researcher noticed how a friendly atmosphere was created at the clinic during interactive sessions between the patients and the nurses and the VCT counsellors. Although the nurses treated the patients as though they were friends, they still maintained their position as information provider.

The researcher observed that the relationship between the individual patients and the nurses was of a more open nature than the relationship with the doctors. Whereas the communication patterns between the patients and the doctors tended to be one-way, provider-led and treatment-centred, the communication patterns between the patients and the nurses tended to be two-way and patient-centred. During the sessions, the patients seemed more comfortable with the nurses and thus communication was more effective with this treatment team member (Observational notes, 13 January 2010). The nurses created a pleasant atmosphere for the patient which was similar to that created by the VCT counsellor (discussed later in this chapter). As communicators, the nurses supplied information successfully to the patients. They also provided care and demonstrated understanding in an empathetic

manner. This reassurance and information ensured that effective interpersonal communication was experienced between these two parties.

As suggested by the KIM, the patients' experience of interactive communication was that it was successful since the nurses' positive attitudes contributed greatly to each participant's understanding HIV, AIDS and ARVs. The nurses displayed effective communicative skills (as discussed above) towards the patients which caused them to feel at ease. The interpersonal relationship experienced between the nurses and each participant contributed to the main health-related goals, consequently, the patients adhered to their medication regimens. In addition, the nurses became part of the social system and shared knowledge openly with each patient. Accordingly, the nurses and patients built up effective relationships throughout their process of interaction thus a transaction of effective understanding of HIV and AIDS and ARVs were achieved (Northouse & Northouse 1985:20–21).

4.5.2.3 *Communication between the patients and the VCT counsellors: learning to live with HIV*

All four of the respondents recounted how the VCT counsellors had assisted them in understanding how to live with their disease. Central to this was the core value of not regarding an HIV-positive diagnosis as a death sentence, but instead making a conscious decision to live a long, healthy and productive life in which adherence to ART becomes a normal routine. This linked directly to the sensitising concept of *perceived susceptibility*, as the VCT counsellors assisted the patient in developing a mindset which regarded HIV and AIDS not as a death sentence but as a disease that one can live with. The reassurance provided by the VCT counsellors that patients "can live" links directly to the sensitising concept of *perceived benefits*, since the exchange of interpersonal communication between the VCT counsellors and the patients facilitated their understanding of HIV and AIDS as well as ARV drug adherence (Janz *et al* 2002:48).

The respondents felt reassured by the counsellors' personal approach when communicating with them. For example Hula commented, "*she explained to me I can live with AIDS, I can play with others laugh at others ... yes, I can live, it doesn't*

mean I am going to die, until God's sake". Samuel expressed himself as follows, "very good, the young guy was very kind the way he explained how I can live with HIV".

Dorothy took some time to think before she responded to the issue of communicating with the counsellors, but eventually she commented: *"Others got moods, others are fine ... In 2006 there were problems, but other counsellors leaving so it's better now ... They teach me to live with the disease, since I am not the only person living with the disease, it's like TB, if you got HIV it's not the end of the life, you can live longer if you change your lifestyle, eat healthy, condomise."* Dorothy thus experienced an improvement in the way in which the counsellors interacted with her over time. Like Hula and Samuel, she felt that the counsellors were less task-oriented in their communication styles than the doctors (who were assessment-centred) and the nurses (who focused on individual symptoms and treatment regimens). It also seems that the counsellors, like the nurses and in contrast to the doctors (who focused on medical issues), attended to the psychosocial needs of the patients (such as how to live with HIV).

Solly felt that the VCT counsellors repeated themselves, meaning that they constantly repeated the same information about drug adherence, how to live with HIV and the aim to become healthier. He commented, *"we understand, talking about the same thing at the same time"*.

The researcher asked the patients to describe the role played by the VCT counsellors in helping them to understand how to use and adhere to their particular ART regimen. Each patient commented very positively and described the education received on ARV adherence and use as highly understandable and said the VCT counsellors used effective communication skills. Hula commented that she had received effective communication from the VCT counsellors. She felt that *"they were speaking the same language, they emphasised do not stop, continue till I die"*. Samuel, like Hula, explained that they were the most effective communicators. He commented, *"each and every day that I met the counsellor new pictures opened in my mind, till today, they are very helpful"*. Dorothy displayed non-verbal cues when she spoke to the researcher; she clenched her hands tightly and maintained direct

eye contact with the researcher and said, *“it’s very important to us since they teach [she is referring to the VCT counsellors] you a lot, but only the first day when you got your status, you were crying, but they didn’t leave us like that ... I was crying on my first day, I was crying, but they helped me”*.

Solly also felt this way as he commented, *“[the VCT counsellors] played a big role in teaching their lessons, we were in the darkness ... They thought us from the beginning, and their patience therefore was good”*. The comments made by Solly and Samuel indicate that the VCT counsellors provided the patients with information-driven education; and thus the core message of how to live with HIV and AIDS as well as ARV drug adherence was effective and fulfilled the needs of these individuals.

The researcher observed (as discussed previously under the theme of *trust and respect*) that the VCT counsellors were favoured by all four case respondents, that is, that they had experienced the most effective communication with them. Furthermore, the patients clearly needed the kind of reassurance offered by the VCT counsellors to persevere. They provided the patient with hope in terms of experiencing the precious gift of life and thus motivated them to carry on living as normal people. This relationship clearly links to the theoretical perspectives of the HBM. The counsellors assisted the individual patients to cope with their diagnosis and still live normal lives. This relationship between these two parties also made the individual patients feel special. In terms of the KIM, a more personal relationship occurred between these two parties with the ultimate intention of achieving health-related goals.

4.5.2.4 *Communication between the patients and the social worker: learning to cope with HIV and AIDS as a social issue*

All four patients explained that they experienced a favourable relationship with the social worker since she educated them effectively during the various interactive sessions. Hula described the education she received from the social worker as *“very nice”* [she smiled when she said this]. She further commented that the work of the social worker was to teach and educate them. Then she said, *“I understood her”*.

Samuel suggested that the social worker played “a major role” in his treatment. He also recounted how he had concerns when people had told him that he could only drink 100% juice whilst receiving treatment. This concerned him greatly as pure fruit juices are more expensive than other cold drinks. However, the social worker took the time to explain to him that he could drink cold drinks, but that he should limit his intake. He also explained that she educated him on the social grant. Samuel’s story reiterated the need for the patients to be treated as human beings, with the medical treatment team members displaying sympathy and care. Patients had concerns about their diets while on ARVs and about the additional costs that might be incurred and affect their household budgets – concerns that the social worker was able to address. If medical treatment team members would take the time to interact and communicate with patients and to treat them as individuals, effective communication could be achieved. The social worker provided the patients with care- and needs-driven communication.

Dorothy agreed that the social worker facilitated her understanding of HIV and ART, as the caring and extra effort made by the social worker facilitated effective communication. Dorothy explained how this team member had educated her on how to take her ARVs and that “*they took their time to listen to us*”. Solly also explained that he had experienced a good relationship with the social worker which facilitated his understanding of his disease and ARVs. He commented: “*The social worker helped me a lot, asking where I come from, my water type, talked a lot, encouraging me....something good for me.*” Access to safe drinking water (and the right type of fluids) was therefore a concern for two of the interviewees. These social aspects of health were better addressed by the social worker than any other member of the treatment team.

The Therapeutic Model posits that a core aspect of the interpersonal relationship shared by the medical treatment team members and patients is to assist the patient to overcome difficult circumstances (Northouse & Northouse 1985:16). The social worker facilitated this role effectively. The social worker was empathetic towards the patient and this allowed the patients to openly share information with her. The attitude displayed by the social worker was one of tolerance since she provided

information that the patients required. She made the patients feel understood since she displayed an honest and sincere demeanour when she interacted with them.

All of the participants pointed out that time is needed with the patient to focus on the individual as a person with their own concerns. The social worker took the time to understand and explain to each patient how to cope and live with their disease. Thus effective communication was clearly achieved which facilitated patients' understanding of HIV and AIDS. The issue of lack of time as a sub-theme was addressed earlier as being a major barrier in the public health system, which can hamper effective communication. Although the aim of the individual patient sessions with the social worker was to perform a psychosocial assessment of the patient, the social worker actively communicated with the patients (see Appendix I: Psychosocial assessment form used during the interactive session). This extra effort on the part of the social worker can be linked to the Therapeutic Model concept of *positive regard* (Northouse & Northouse 1985:17). The social worker displayed a positive attitude towards the patients which facilitated effective patient-need centred communication (Observational notes, 6 January 2010).

4.5.2.5 *Communication between the patients and the pharmacist assistant: education on ART*

A group lecture hosted by the pharmacist assistants was held on 13 January 2010, during which the researcher was an observer. The purpose of this lecture was to educate patients from the drug literacy classes who were embarking on ART. This session was aimed at introducing new patients to the basics of ARV drugs, the different regimens available, the possible side effects that can occur and adherence plans. During this lecture, the pharmacist assistants reiterated information that patients had already been given and, like the nurses, VCT counsellors and social workers, provided information-driven education dealing with HIV and AIDS and ART.

All four patients agreed that this lecture facilitated their understanding of ARVs and thus effective the information was communicated effectively. Hula commented: "*Yes, I understood about ARVs, they explained about this, if you using ARVs you're boosting your immune system, ARVs help your immune system, clear explanation*".

Samuel stated that the assistants' communication was "*also right*" and that he understood how to take his medication. He added that the public health care system is overloaded; resulting in long queues, but that because they are dependent on the system they have to tolerate it and be patient. According to Dorothy, the pharmacy assistants dealt with defaulters and "*educate you how to take medication*". Solly informed the researcher that he had engaged interactively with the lecture since he had asked questions and had been given answers by the pharmacy assistants; he explained: "*The lecture was trying to make us not forget what we learnt before, it was a lesson, but it was good*".

According to Northouse and Northouse (1985:17), the assistants (as the helpers) and the patient (as the helped) interact with each other and, by establishing *congruence*, provide information which ensures that communication is *real* and thus effective. All four case studies understood the core message of this session, thus their information needs were satisfied. The concept of *cues to action* (which stems from the HBM) was demonstrated as being a central idea in the group session, as patients were taught stratagems for constantly reminding themselves to take their ARVs (such as pill boxes and other reminders). Moreover, the concept of *perceived benefits* is used to understand how the assistants interactively engaged with the entire group in providing information on the correct use of ARVs (Janz *et al* 2002:49).

In the observational notes taken during this group session, the researcher detected the way the non-verbal cues given by the pharmacist assistants were used to convey a positive attitude. If the concept of *positive regard* is thus applied to this observation, it can be concluded that the pharmacist assistants displayed tolerance when they lectured to the patients. In addition, they gladly accepted questions during the interactive session. The researcher observed that when Solly asked many questions, they readily responded to all of them without becoming irritated or annoyed with these interruptions. This attitude contributed positively to the treatment system provided at the ARV clinic and facilitated an open sharing of information during this group session (Northouse & Northouse 1985:17).

4.6 SUMMARY IDEAS: INSTILLING HOPE

Cognisance should be taken of the fact that the communication between patients and the various treatment team members overlapped and mutually influenced the understanding of the patients of their illness and treatment regimens. Taken as a whole, the various efforts at establishing communication with the patients converged in the sub-theme of **reassurance and hope**. The entire treatment team aimed at educating all four patients on HIV and AIDS and the correct use of ARVs. The issue of adherence was brought up constantly throughout the individual and group sessions. Patients understood the adherence and thus received effective communication. This sub-theme further emerged in the responses the researcher received from the individual patients when she asked them to provide an explanation of what they understood ARVs to be.

Hula explained her understanding as follows: *“The [Hi-} virus affects the cells so that ARVs boost the cells not to become tired because of the virus. And the virus is multiplying in the body. ARVs protect you from other diseases that can come through.”* She also explained the different types of ART regimen to the researcher.

Samuel described it as the following: *“Antiretroviral medication is medicine that will help me to live longer than I have to. I would have died quicker without it.”* He described it as medication that will help him become healthier and thus be able to live longer.

Dorothy described her regiment as: *“Antiretroviral, I am on regiment 1A. My understanding is that it does not cure ... it helps me to keep my CD4 count high and my viral load low.”* She was knowledgeable about the different drugs that constituted her regiment, but found it hard to explain them in lay terms.

Solly said, *“ARVs are medication that helps to reduce the virus in the blood, not treating as such, sort of reducing”.* Solly seemed nervous and played with his hands and looked down when he answered this question. The researcher gathered that he might feel apprehensive as he was only just starting with the treatment.

All of the patients seemed to have received effective communication from the various treatment team members. As demonstrated above, they were reassured and thus became hopeful that ARVs would help them lead a healthier life. They were educated that ARVs would give the HIV-infected person hope to persevere. This finding links directly to the HBM concept of *perceived benefits*, as the patients received reassurance that ARVs would assist them to become healthier (Janz *et al* 2002:49).

All four case studies were dependent on the treatment offered at the ARV clinic and thus they all judged the services provided as beneficial and positive, with no direct criticism of any of the services rendered. Nevertheless, the power differential and the superiority of the medical doctor as the most knowledgeable treatment team member were revealed and commented on. Although the patients experienced problems with the health care system, they tolerated them because they were dependent on the system for health care and treatment.

The four patients were asked to comment on whether the treatment team members were aware of cultural beliefs. All of the patients except for Solly, agreed that the medical team members were aware of cultural and traditional remedies and their effects on ARVs. Only Solly remarked: *"No! Medical staff doesn't know."* Samuel said: *"Medical staff are aware but undermine the other one."* He believed that cultural traditions should not be undermined by the team members. Dorothy commented in a confident tone: *"Yeah, they know very well, they're dealing with it"* as if she assumed that the medical team members were addressing traditional customs as part of the treatment. Hula commented that the team members are quite aware since *"they are human beings therefore they know"*. Hula felt that cultural traditions were human knowledge and therefore she assumed that everyone would be aware of traditional remedies. From her observations, the researcher also found that the treatment team members were aware of cultural beliefs. In the drug literacy training session hosted by the pharmacist assistants, the issue of herbal remedies was discussed and it was made quite clear to the patients that they could not take any herbal remedies in conjunction with ARVs. The lecture also provided examples of herbal medicines they should avoid while on ARVs (Sankar 2005:18).

When, in the face-to-face interviews, the individual patients were questioned on their awareness of any cultural, religious or traditional beliefs that could hinder ART, the patients expressed different views. Samuel remarked that non-mainstream and mainstream medicine should be offered in conjunction. He commented: *“If they can allow the herbal doctors to be involved in the lab when making ARVs, they would maybe speak a new language that AIDS is not curable ... God gave us trees and plants to use them.”* Solly opposed this view and was doubtful that traditional remedies could help as he said *“people are looking for money, but I doubt a sangoma can treat HIV”*. Dorothy commented, *“In my church they were supportive, not against ARVs”*. Hula reiterated the messages given by the treatment team members and declared: *“We have to use ARVs, Just ARVs [she said this in a very forceful tone]. They teach us not to take any other medication than ARVs”*. However, she did mention that *“there are some other churches that do not use [condone the use of] any tablets, not even pain killers.”*

4.7 CONCLUSION

The core focus of the study was on interactive communication and the way in which the various sessions at Stanger hospital with the various role-players in the treatment team either facilitated or hampered patients' understanding of HIV, AIDS and ART. The major themes that emerged from the data included interactive communication, the education and information needs of patients, and trust and respect. Lack of time and privacy in the public health care system emerged as possible factors that hamper health education. Communication between the nurses, VCT counsellors, social workers and pharmacist assistants were characterised by reassurance and hope.

The data seem to suggest that all four research participants experienced effective communication and thus understood their disease and how to use ARVs. However, they all mentioned that the doctor was the superior treatment team member and the most knowledgeable in the treatment process. They thus tended to comply with the biomedical treatment approach. All four participants were dependent on the public health care system and thus relied on the clinic for access to ART. Therefore, they

judged the services received as beneficial and positive. The following chapter will conclude the study and research recommendations will be made.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

The central research question of the study was how the communication process at Stanger hospital facilitates or hampers patients' understanding of HIV, AIDS and ART. This chapter concludes the study by juxtaposing the set research objectives with the findings. In this chapter the researcher reflects on the way in which the chosen research design enabled effective data generation. The strengths and limitations of the study are outlined and, finally, recommendations are made for further research, policy and programme development for Stanger hospital.

5.2 RESEARCH OBJECTIVE 1: DOES INTERACTIVE COMMUNICATION FACILITATE OR HAMPER PATIENTS' UNDERSTANDING OF HIV AND AIDS AND ART?

It was found that patient education conducted by means of the drug literacy classes, coupled with deliberate efforts made to build a relationship of trust between patients and certain treatment team members, facilitated patients' understanding of HIV, AIDS and ART. This linked up directly to the empowerment theoretical framework as outlined in chapter 2. During the interactive sessions, the patients were educated on various aspects relating to their condition. Patients favoured this type of knowledge exchange since it made them more aware of the medical aspects of their disease.

5.3 RESEARCH OBJECTIVE 2: HOW DOES THE PATIENT COMMUNICATE OR INTERACT WITH THE DIFFERENT MEDICAL STAFF MEMBERS?

As reported in chapter 4, the study found that all the patients displayed positive attitudes with regard to the treatment and care they received from the various medical professionals. They did not spontaneously mention any negative aspects of the sessions with treatment staff. This was especially the case in terms of the medical doctors. The researcher interprets this as stemming from the patients'

dependence on the treatment they received from the hospital. Owing to their financial circumstances, they were reliant on the public health care system and thus refused to speak ill of it. However, the researcher observed that the problem of power differentials arose, which hampered effective communication between the doctors and the patients. This could be interpreted in terms of the theoretical concept of *perceived benefits* from the HBM, as the doctors did not try to allay the patients' fears about ART medication (Janz *et al* 2002:49) and this resulted in ineffective communication. The concept of *modifying factors* further provided a hook on which to hang the interpretation of the communication as characterised by the unspoken acknowledgement of the superiority of the medical doctor. Patients were thus positioned as subservient to the doctors and this discouraged more open, two-way communication (Northouse & Northouse 1985:19).

The patients reported effective communication with the nurses in that they experienced it as patient-centred, rewarding and helpful. The patients were more able to communicate openly with the nurses when they needed to discuss medical concerns. Thus the nurses were successful in convincing the patients of the *perceived benefits* of ART, and communication was successful and thus effective in educating the patients on the effectiveness of ART (Janz *et al* 2002:49). The HBM concept of *perceived severity/perceived threat* can be used to analyse patients' concerns about the social consequences of disclosure (Janz *et al* 2002:48). In this regard, the nurses helped the patients to cope with their disease and with the difficult task of disclosure. The nurses and patients experienced effective relationships throughout their interaction process, thus a transaction of effective understanding of HIV and AIDS and ARVs was achieved (Northouse & Northouse 1985:20–21).

The VCT counsellors communicated interactively with the patients and educated them on how to live with their disease. They supported the patients in achieving a healthy life by means of adherence to ART. The positivity displayed by the VCT counsellors motivated the patients to see HIV as a disease that one can live with as opposed to a death sentence. This positive attitude produced on the part of the counsellors ensured that the patients' perceptions were altered positively in terms of the *perceived benefit* concept of the HBM (Janz *et al* 2002:48). The patients trusted and respected the counsellors thus communication was effective and they

understood how to adhere to ART. In terms of the KIM, the VCT counsellors and patients shared a close interpersonal relationship during which a *transaction* occurred with the goal of ensuring ART adherence (Northouse & Northouse 1895:20).

The social worker acted as a positive role-player in providing effective communication about coping with HIV and AIDS as a social issue. All of the patients reported that they understood the communication they received from the social worker and felt comfortable enough to ask various questions. By using the Therapeutic Model as a lens, it is possible to view the role of the social worker and her tolerant and empathetic attitude as being key to assisting the patients to overcome difficult situations (Northouse & Northouse 1985:16). The social worker provided the patients with care- and needs-driven communication.

The pharmacist assistants provided ART education to the group of patients. Much of the information provided during this lecture was on how to use ARVs, adherence therapy and possible side effects to the treatment regimen. This education was information-driven, dealing with HIV, AIDS and ART, and was delivered with a positive attitude towards the treatment system; thus, effective communication was achieved (Northouse & Northouse 1985:17).

5.4 RESEARCH OBJECTIVE 3: WHICH FACTORS FACILITATE AND WHICH FACTORS HAMPER AN OPEN SHARING OF INFORMATION?

Lack of time and privacy emerged as hampering factors in the open sharing of information between medical professionals and patients in the health care system. Patients are rushed as a result of time constraints and the medical staff members spent only about five minutes with each patient during the interactive sessions. Thus staff shortages hamper effective communication in the public health care system (Observational notes, 11–13 January 2010). Privacy is almost non-existent at the hospital, and during the drug literacy classes patients are squashed into a venue that was too small and offered no anonymity.

Despite these largely structural constraints, the researcher found that human factors, such as the efforts made to instil trust and respect (especially on the part of the VCT counsellors), facilitated effective communication. Each of the respondents reiterated that the VCT counsellor was their best educator and thus was the one they most respected, especially since they educated and thus empowered patients. Moreover, they were seen as kind and compassionate and treated all patients with respect. The counsellors aimed at altering the *individual perceptions* of patients by educating them on how to live with HIV (Janz *et al* 2002:52).

In addition, in findings reassurance and hope emerged as themes, describing factors that facilitated effective communication. The entire treatment team assured the patient that it was important to accomplish and maintain adherence and that, if this were done; they would be able to keep their disease under control. Thus patients became hopeful of living long, happy and healthy lives despite being HIV positive.

5.5 STRENGTHS AND LIMITATIONS OF THE STUDY

A limitation to this study was the sample size. Owing to the limited sample size involved, findings cannot be generalised to the entire hospital population or to all HIV patients. However, the goal was to analyse interactive communication on an in depth level and thus a qualitative methodology was adopted. By focusing on four case-studies, the researcher was able to generate rich data and thus this represents one of the strengths of the study.

The recruitment of participants for this study turned out to be difficult. This emphasises that, although HIV is a common disease, it is still highly stigmatised. This worked was a limitation since the researcher was hopeful that younger patients would volunteer to participate in this study; however, they were very reluctant and refused to be part of the study.

A major strength of the research was the use of the four different theoretical frameworks namely, the HBM, the KIM, the Therapeutic Model and insights of empowerment theory, as explained in detail in chapter 2. This allowed the

researcher flexibility and was well suited to the “open”, flexible approach chosen for the research, as concepts from the various models were used as sensitising notions.

5.6 RECOMMENDATIONS FOR FURTHER RESEARCH

The study was able to provide answers to all the stated research questions. However, it is recommended that research be conducted on a larger scale with more hospitals and more patients. The study found that, despite structural constraints (staff shortages, lack of suitable venues, lack of time, lack of privacy); human factors such as empathy, respect and tolerance can build effective health communication in respect of ART. An extension of this could be further research into the resilience of treatment team members to continue playing this role and into ways of addressing structural constraints. A further recommendation in this regard would be to do more research on the ‘internal dynamics’ of medical treatment teams, as medical professionals are mutually dependent on each other in the work that they do. As noted in this study the patients undergo a treatment process during which they interact with various medical staff; thus, staff members need to work together to ensure treatment effectiveness. If the chain in this treatment process is broken as a result of poor internal dynamics, adherence to treatment may be affected.

5.7 RECOMMENDATIONS FOR POLICY AND PROGRAMMES

The researcher is well aware that her findings cannot be generalised to the entire hospital population however, based on her findings and mastery of the literature on the topic she makes some tentative suggestions. At the level of theory, it is recommended that existing health communication models be extended to cater for culture as a concept that can facilitate or hamper a patient’s understanding of HIV and AIDS and ART. Such a model should be cognisant of the strengths, weaknesses, opportunities and threats inherent to the South African public health care setting.

5.8 RECOMMENDATIONS FOR STANGER HOSPITAL

In the South African public health care system there is an urgent need for more staff. In addition, since public hospitals have limited space for hosting scheduled lectures, such as the drug literacy classes and ARV lectures, a lack of privacy emerges as a major factor that hampers effective communication. HIV and AIDS is still a highly stigmatised disease and thus medical institutions need to respect a patient's right to privacy.

For Stanger hospital in particular, the erection of more facilities and donation of chairs could be explored as practical matters that could go a long way to making life easier for its dedicated staff and its patients. The staff (in particular the VCT counsellors) who despite the large numbers of patients, the lack of space, time and privacy render patient-centred care, should be commended. The fact that each treatment team member is able to address a particular communication need of HIV-positive patients accessing ART should be emphasised as a central strength that underscores the value of a team approach to the treatment of HIV as a chronic illness.

The researcher wishes to point that, during her research process, she visited the hospital regularly; consequently, she noted that there are other VCT counsellors working at the hospital, some of them were stationed to working with patients in the out-patients (OPD) department. She wishes to suggest that if all the counsellors work together in giving the drug literacy classes, as well as treating the new patients entering the system for treatment, the work can be shared between more counsellors at the hospital, instead of just three who are stationed at the ARV clinic. Moreover, more medical doctors from the out-patients department could assist the ARV medical doctor during these busy times; that is, when new patients are entering the medical system for ARV drug treatment. The researcher believes that this extra help will go a long way in the treatment process for both medical staff and patients.

The researcher noted that all the case studies seemed very keen and eager to embark on ART since they were educated that it will help them become healthy again. In this regard, to keep up the enthusiasm of the patients it is suggested that

the hospital ensure that all patients have at least three visits with the psychologist at the hospital to ensure that they have a mental assessment done in order to access if they are depressed or not since this can play a major role in non-adherence of their medication. The psychologist can aim to empower patients in these sessions and motivate them to read and become more educated towards their new disease and thus become empowered by taking control of their lives and in this way they can avoid psychological noise in the treatment process.

The study concludes that the communication process which occurs at the ARV clinic at Stanger hospital is, on the whole, satisfactory. However, what is “missing” from the communication is the peer modelling/education on how to live with HIV and be adherent to ART. In this regard, communication could be conveyed in the context of a support group, which should be set up at the hospital. This might further help patients to cope as they would be able to learn from others’ experiences.

5.9 CONCLUSION

This study has achieved its goal of providing a descriptive analysis on the interactive communication process that occurs between patients and medical care providers at Stanger Regional Hospital's ARV clinic. Interactive communication was favoured by all the patients and thus was effective in educating patients. In this regard, Suchman, Bothelo and Hinton-Walker (1998:3) state:

“the mission of improving the nation’s health care system has three interrelated goals: to provide more equitable access to health care; to enhance the quality of health care; and to improve the economic performance of the health care delivery system. Each of these goals has implications for and depends upon partnerships throughout the system.”

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APPENDIX A: OBSERVATION SHEET: OF A 'SIT-IN' SESSION WITH THE MEDICAL PROFESSIONAL AND THE PATIENT

Case-study: 1 (Patient: A) _____
Occupation of medical professional: _____
Position and job title at Stanger hospital: _____
Date and time: _____
Length of session: _____

How does the medical professional greet the patient? How does he/she address the patient?
Does he/she take time to establish trust?

Who takes the lead/initiative in the interaction?

How does the medical professional speak to the patient? (Tone, eye contact, language, medical jargon)

How and when are issues related to ARV medication introduced? Is treatment adherence discussed? Are changes/threats to adherence assessed, monitored, tested?

How does the patient react to the medical staff? What does the patient say and do regarding treatment and adherence?

What non-verbal cues does the researcher notice from the medical staff and the patient during the session?

Are questionnaires, forms or other written material used during the interaction?

Questions posed by the medical professional

Questions posed by the patient

Issues/questions left unresolved during the session

How is the session concluded?

Other comments

APPENDIX B : INTERVIEW SCHEDULE

Please note that this is an incomplete schedule as questions will added guided by the researcher's observations during the various 'sit-in' sessions.

Hallo, I am Miss Moola. Firstly I would like to extend my gratitude to you for agreeing to be part of this study. As I have already explained, the aim of this study is to observe the communication process between medical staff and patients at this hospital. We have signed the consent form and I have explained the aims of the study. Please remember that you may withdraw from the study or stop the interview at any time. Your identity will remain confidential at all times.

1. Case-study: 1

2. Age:

3. Gender:

4. Language, ethnicity, cultural identification:

5. Thinking back over the various sessions you have had with the staff here at the hospital, please describe to me how you see the role played by each of them in helping you to understand how to live with your disease:

5.1 First, the doctor?

5.2 The nurse?

5.3 What about the VCT counsellor?

5.4 How do you see the role of the social worker?

5.5 And the pharmacist assistant?

6. Please describe to me what ARV medication is?

7. How would you describe the role played by each of the following medical staff in helping you to understand how to use your particular ART regime and adhere to it?

7.1 Doctor

7.2 Nurse

7.3 VCT counsellor

7.4 Social worker

7.5 Pharmacist assistant

8. Which member of the medical team do you personally regard as the person who has given you the most (or most helpful) information on how to use your ART regime? Probe: Why do you say so? If interviewee regards none as being helpful ask: which other sources of information do you access and why.

9. In your opinion what is successful communication between you as a patient and the medical staff? (Explain how you would understand ARV adherence, how you would prefer the medical team to educate you on HIV and ARV medication?)

10. How easy is it for you to communicate with each of the medical staff? Probe: Tell me about problems you have encountered as far as communication is concerned. What happened? Do you know why it happened? Were you able to resolve it?

11. Which member of the medical staff do you feel most comfortable to talk to? Why is this so?

12. Which member of the medical staff do you feel the least comfortable to talk to? Why is this so?

13. Have you ever felt too scared, ashamed or intimidated to ask a question regarding your treatment? Please tell me about it...

14. What is the best piece of advice you have ever received regarding your treatment regime? Who gave you this advice?

15. Let's imagine a hypothetical situation where you perhaps defaulted on your treatment regime – you were therefore not completely adherent. If something like that should ever happen to you – would you tell the staff here about it? Would you rather keep quiet about it? Probe: reasons, whom the interviewee would confide in.

16. Do you discuss your ARV treatment regime with your family? Are they supportive? Probe.

17. Is there anything in your ARV treatment regime that you find particularly difficult to follow? Does it fit into your lifestyle? Probe. Did you discuss this with anyone here at the hospital? Probe

18. As an HIV-positive person using ARVs, are you aware of any cultural, religious or traditional beliefs that may support or hinder treatment adherence? Can you tell about this? Do you think the medical staff is aware of these beliefs?

19. If you could change anything in the consultation and communication process between you and any of the members of the medical staff – what would you change and why?

APPENDIX C: CONSENT AND INDEMNITY FORM

Dear Participant

Hello, my name is Sabihah Moola and I am a lay counsellor and a MA-student at the University of South Africa. You are invited to be part of a study which aims to analyse the communication process between HIV-positive patients and medical staff at the Stanger Provincial Hospital's ARV clinic. The VCT counsellor has identified you as someone who might be willing to participate.

First, however, I want to tell you exactly what participation in this study would entail. Note that participation is **completely voluntary** which means that you can refuse to take part or withdraw your participation at any time without suffering any penalties. There are **no incentives** paid for participation and there may be no direct benefits to you, however your participation will help us with information that might benefit other patients at the hospital who are entering the medical system for ARV medication. Please note that all information you provide in this study is treated as **highly confidential**. Your name will only be known to me and the VCT counsellor, but in writing up the data, personal identifying information will be removed. This means that **your true identity will remain a secret** and your name and true identity will not be revealed to anyone else or be made public when the data is written up. The only place your name will be recorded is on this information sheet and informed consent form. These sheets are kept in a locked cabinet and your name will never be used in any of the research outputs.

If you agree to participate in the study, I would sit in as a silent observer in your meetings or consultations with the doctor, the nurse, the VCT counsellor, the social worker, psychologist, dietician and the pharmacist assistant. My goal will be to observe the communication process between you and the medical staff and I shall make notes on my observations. These meetings will not be tape recorded. After observing your interaction with the medical treatment team, I shall conduct a brief personal interview with you and ask you a view questions about your experiences here at the clinic. This personal interview will be tape recorded. All my notes, tape-recordings and transcriptions will be treated as extremely confidential materials and I shall keep them securely locked away.

Please note that my presence in your consultations and the interview will not interfere with your treatment here at the clinic and that, should you refuse to participate or wish to stop participating at any stage, this would also not affect your treatment here.

I

f you have questions about the study you may ask them now or you can call: 082 8420074

If you don't have any questions and agree to participate in this study then I will ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate in the study. This is the only place where your name will be entered. If you do not wish to sign your name, you may simply mark the space with an 'X'.

Volunteer's statement

THE STUDY (INCLUDING THE OBSERVATIONS AND THE INTERVIEW) HAS BEEN EXPLAINED TO ME. I HAVE BEEN GIVEN A CHANCE TO ASK ANY QUESTIONS I MAY HAVE AND I AM CONTENT WITH THE ANSWERS TO ALL OF MY QUESTIONS.

I ALSO KNOW THAT:

1. MY RECORDS WILL BE KEPT PRIVATE AND CONFIDENTIAL.
2. I CAN CHOOSE NOT TAKE PART IN THE STUDY, NOT TO ANSWER CERTAIN QUESTIONS, OR TO STOP AT ANY TIME.
3. IF I REFUSE TO BE INTERVIEWED, IT WILL NOT AFFECT MY MEDICAL CARE AT THE CLINIC.
4. I GIVE CONSENT THAT THE PERSONAL INTERVIEW CAN BE TAPE-RECORDED.
5. I UNDERSTAND THAT THE INFORMATION COLLECTED FROM VARIOUS VOLUNTEERS WILL BE ANALYSED AND REPORTED ON AS FINDINGS OF THE STUDY, BUT THAT ALL IDENTIFYING DETAILS THAT LEADS BACK TO ME WILL NOT BE DISCLOSED.
6. I UNDERSTAND THAT THE INFORMATION COLLECTED THROUGH THIS STUDY WILL BE WRITTEN UP AS A RESEARCH REPORT AND AS A DISSERTATION AND I GIVE CONSENT THAT MY RESPONSES MAY BE QUOTED AS LONG AS MY TRUE NAME AND IDENTITY IS NOT REVEALED.

_____	_____	_____
Date	Name of volunteer	Signature or Mark of Volunteer

_____	_____	_____
Date	Name of witness	Signature of Witness

APPENDIX D: ETHICAL APPROVAL FOR STUDY FROM URERC



PROF T S MALULEKE
EXECUTIVE DIRECTOR: RESEARCH
☎ : +27 12 429 2970/2446 ☎ : +27 12 429 6960
☎ : +27 (0)82 925 5232 ☎ : malults@unisa.ac.za
📍 Theo van Wyk Building, 10th Floor, Office no. 50 -52 [Tvw 10-50-52]

10 November 2009

Ms Sabihah Moola
31 Torremolonos
Epworth Street
Queenswood
0186

Dear Ms Moola

REQUEST FOR ETHICAL CLEARANCE: The communication process between HIV-positive patients and medical staff: A study at Stanger regional Hospital's ARV clinic

Your application for ethical clearance in respect of the above study has been received and was considered by the Unisa Research Ethics Review Committee on 4 November 2009.

The Committee is pleased to inform you that ethical clearance has been granted for the above study. The Committee notes with approval your explanation regarding the selection of HIV-patients in your letter dated 5 November, as requested in our electronic communication dated 5 November.

The permission granted must not be (mis)construed as constituting an instruction from UNISA Management that the relevant participants are compelled to take part in the research project. All participants retain their individual right to decide whether to participate or not, as you explained in your research proposal.

We trust that sampling will be undertaken in a manner that is at all times respectful of the rights and integrity of those who volunteer to participate, as stipulated in the Unisa Research Ethics Policy, which can be found at the following website:

http://www.unisa.ac.za/contents/research/docs/ResearchEthicsPolicy_apprvCounc_21Sept07.pdf

Congratulations on an interesting and very relevant study. We would like to wish you well in this research undertaking.

Kind regards,




PROF T S MALULEKE
EXECUTIVE DIRECTOR: RESEARCH

cc. PROF M C MARÉ
PROF M N SLABBERT



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**APPENDIX E: PERMISSION FROM FACILITIES- STANGER
HOSPITAL MANAGER: DR. AJ MANSVELDER**

	DEPARTMENT OF HEALTH	
	PROVINCE OF KWAZULU-NATAL STG. HOSP. – CHIEF EXECUTIVE OFFICER	
STANGER HOSPITAL CNR OF KING SHAKA AND PATTERSON STREET STANGER E-mail: Mansvelder.Adri@kznhealth.gov.za	Tel: 032-4376200 Fax: 032 6516492	STANGER HOSPITAL PRIVATE BAG X10609 STANGER, 4450
Enquiries: Dr. A.J. Mansvelder Ext: 6200		
9 November 2009		
Principle Investigator: Miss Sabihah Moola		
<u>RE: PERMISSION TO CONDUCT RESEARCH AT STANGER HOSPITAL'S ARV CLINIC</u>		
I have pleasure in informing you that permission has been granted to you by the District Office/Facility to conduct research on: The communication process between HIV-positive patients and medical staff: A study at Stanger Regional Hospital's ARV clinic.		
Please note the following:		
<ol style="list-style-type: none">1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.3. Please ensure this office is informed before you commence your research.4. The District Office/Facility will not provide any resources for this research.5. You will be expected to provide feedback on your findings to the District Office/Facility.		
Thanking you. Sincerely,		
		
CHIEF EXECUTIVE OFFICER DR. A.J. MANSVELDER		
<i>Umyango Wezemphelo</i>		<i>Departement van Gesondheid</i>

**APPENDIX F: PERMISSION FROM FACILITIES- ILLEMBE HEALTH
DISTRICT MANAGER: MS S. DUBE**

05/01 2006 08:08 FAX 0325511425

ILLEMBE HEALTH DISTRICT

05/01



HEALTH
KwaZulu-Natal

MEMORANDUM

Tel: 032 – 4373500
Fax: 032 – 5511590
E-mail: sibongile.dube@kznhealth.gov.za
www.kznhealth.gov.za

TO	: MS SABIHAH MOOLA
FROM	: MISS DUBE
DATE	: 09 NOVEMBER 2009
RE	: RESEARCH PROPOSAL: MASTERS IN SOCIAL AND BEHAVIOURAL STUDIES IN HIV AND AIDS
INDEX NO	: DM09/11/1975

This is to inform you that your request for doing research for masters in Social and Behavioural Studies in HIV and AIDS in this district is supported. This is on the provision that you will obtain approval for conducting the study by the Departmental Ethics Committee under the chairmanship of Dr. SSS Buthelezi.

Yours faithfully

S. Dube – District Manager
Ilembe Health District – DC 29

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX G: PERMISSION FROM FACILITIES- DEPARTMENT OF HEALTH KWAZULU-NATAL (UNDER THE LEADERSHIP OF DR SSS BUTHELAZI)



Health Research & Knowledge Management sub-component
10 – 102 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg, 3200
Tel.: 033 – 395 2805
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference: HRKM134-09
Enquiries: Mr X. Xaba
Telephone: 033-395 2805

20 November 2009

Dear Ms S. Moola

Subject: Approval of Research

1. The research proposal titled "**The communication process between HIV-positive patients and medical staff: A study at Stanger Regional Hospital's ARV clinic**" was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for the study to be undertaken at Stanger Regional Hospital.

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

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

Yours Sincerely

Dr. S.S.S. Buthezi

Chairperson: Provincial Health Research Committee
KwaZulu-Natal Department of Health

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX H: DRUG LITERACY WORKSHOP MANUAL

MASOTHOLE PATRICIA LANGA

**DRUG LITERACY
WORKSHOP
MANUAL**



**KZN Department of Health
Patient Treatment Literacy**

Module 1 Stigma, Disclosure & Positive Living

KZN Department of Health
Patient Treatment Literacy

- ### Topics to be covered...
- **Overview**
 - KZN Comprehensive Care Programme
 - Who needs ARV therapy
 - What to expect before you start ARVs – training & testing
 - What to expect after starting ARVs – follow-up appointment
 - **Stigma**
 - Associated with being HIV-positive
 - **Disclosure**
 - as a means to gain support
 - **Positive Living**
 - Physical health
 - Nutrition
 - Mental health

Next few weeks...

For every person who tests HIV-positive

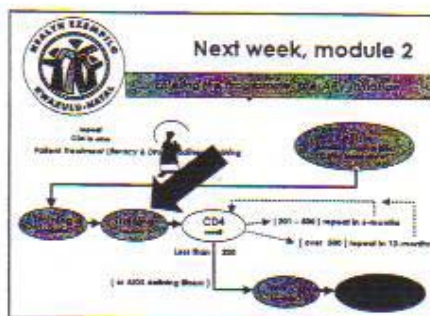
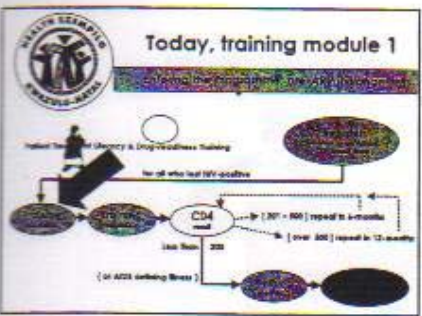
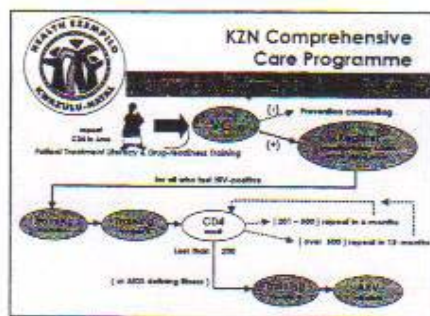
- There will be training today (module 1)
- And training next week (module 2)

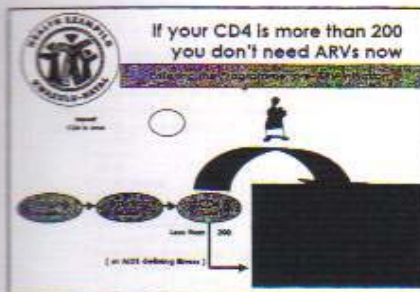
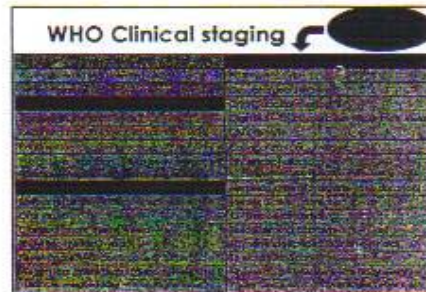
You will receive the results of your CD4

- Persons with CD4 less than 200 or who have an AIDS defining illness → will start ARVs
- Before starting ARVs, you will have one more training session (module 3)

Training

- In order to start ARVs, every person must attend all 3 training modules





Empowerment

- These sessions will build your knowledge about HIV/AIDS & ARV treatment

Knowledge is power
↓
power is life!

- You will become equipped to deal with HIV in your life
- You will be able to teach & empower others

Pledge of Confidentiality

- In addition to learning, we must have the chance to share our feelings, questions & concerns
- Each person here today, must pledge to respect and protect the confidentiality of every one in this room
- All stories shared must remain within this group - unless permission is given by the persons sharing their story
- Today we will address the issue of STIGMA & the importance of DISCLOSURE of our HIV status...

Stigma

Can you hear the silence?

Stigma causes us to be silent about HIV

what is stigma?

- Attaching a negative label to someone
- may be based on partial truth or false information
 - many things can be stigmatized:
 - poverty
 - divorce
 - stress
 - family troubles
 - being in jail
 - being arrested
 - look, dress or talk different
 - using alcohol or drug
 - associating with the 'wrong' people
 - being HIV-positive

behaviors due to STIGMA...

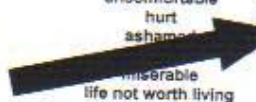
- talk about people behind their back (gossip)
- avoid someone who is stigmatized
- laugh / tease / make fun of someone

persons receiving STIGMA may feel...

embarrassed
uncomfortable
hurt
ashamed
depressed
miserable
life not worth living
isolated and alone
want to kill themselves

persons receiving STIGMA may feel...

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two sources of STIGMA

1. External Stigmatization

Stigma toward us that comes from others (neighbors, family, friends, parents, children, co-workers, community, church members, doctors, nurses, teachers, etc.) who are external / or outside of us. It is other people judging or discriminating against us.

2. Internal Stigmatization

Stigma that comes from within us. It happens if we let ourselves believe in or accept the stigma. It happens if we believe we deserve to be treated badly or differently because what we are being is somehow our fault.

effects of EXTERNAL STIGMA (from others)

- withdraw or isolate themselves for protection
- keep worries & troubles inside to avoid more stigma
- avoid seeking help from others to prevent rejection

effects of INTERNAL STIGMA (from within a person)

- Persons with HIV/AIDS may have trouble accepting themselves and their HIV-status because they accept or even believe the stigma.
- They believe that being HIV-positive means they are bad or did something wrong.
- They believe they deserve the stigma.

fears caused by HIV STIGMA...

1. HIV+ persons fear being treated differently
2. HIV+ persons fear they will lose support
3. HIV+ persons fear friends & family will stop loving them

involuntary disclosure

1. Verbal disclosure
You tell someone your status with words
2. Symptomatic disclosure
Symptoms due to HIV disclose for you. People guess your status because you look sick. (Examples: you may develop TB and they see you coughing, or you may become very thin, or you may get diarrhea, or you may get a rash, etc.)
3. Behavioral disclosure
When your behavior due to HIV disclose for you people guess your status because you act or behave sick. (Examples: you change the temperature, or because of HIV, you not go out, stop going to work, stop spending time with friends, appear depressed, etc.)

(3) kinds of disclosure...

1. Verbal disclosure
You tell someone your status with words
2. Symptomatic disclosure
Symptoms due to HIV disclose for you. People guess your status because you look sick. (Examples: you may develop TB and they see you coughing, or you may become very thin, or you may get diarrhea, or you may get a rash, etc.)
3. Behavioral disclosure
When your behavior due to HIV disclose for you people guess your status because you act or behave sick. (Examples: you become too weak and can no longer do the things you did before - like work or feed yourself, or because you become so depressed you no longer act the way you did before.)

why is VERBAL DISCLOSURE preferred?

1. When you have not told someone your status
→ they can only guess or speculate about your status.
2. They don't really know for sure
→ but they will talk about it as if they know!
→ usually they say negative things.
→ this kind of negative talk is hard on HIV-positive persons.
3. If you come out and tell your status
→ there is nothing left to talk about.
4. They can't whisper behind your back you are positive
→ if it is already known.
5. It becomes old news
→ and the truth does not make good gossip.

...why VERBAL DISCLOSURE?

(continued...)

8. Verbal disclosure is something you control.
9. You decide when and how.
10. Verbal disclosure takes courage
11. The courage for verbal disclosure comes from knowledge
→ which gives you power
12. When the silence is broken around HIV/AIDS
→ people can begin to work together
13. People can look for answers
→ Instead of promoting ignorance and bad behavior.

steps to disclosure

- Accepting and loving yourself
→ is extremely powerful
- When you love yourself
→ others will learn from you
- When you expect love and acceptance after disclosure
→ it will be given to you

SUMMARY

Why is disclosure so important?

- Keeping HIV-status a secret causes much stress/fear
→ Sharing the burden of HIV-status relieves stress/fear
- Disclosure gives the opportunity to educate others
→ knowledgeable persons can be supportive of you
- Traveling to your clinic visits requires support
→ Family will understand why you need transport fees to clinic
→ Family will help with household work while gone
→ Family will help with care for children while gone
- If you are going to start ARVs - you will need support
→ Disclosure will bring persons to remind you to take your meds
→ Educating your family will prevent medication sharing

positive living

What is *positive living*?

- It is a **new way of thinking** or of facing the daily challenges of life – and is essential when facing something as difficult as living with HIV-infection.
- It is **turning away from negative thinking**, which is not only unproductive, but actually has a negative impact on your health.
- It is adopting a **'positive' approach to life**
- It requires many changes to take place - starting from the **mind** (thoughts and attitudes), **behavior** and **life style**.

Where to begin...

- **Believe:** you can live productive healthy life irrespective of the presence of HIV/AIDS in your life.
- **Let go of Stress:** Identify the situations that cause you stress. Look for ways to change the situations or relieve the stress they cause.
- **Seek Support:** Find the persons who will support and love you. Ask them to stand by you & help you on your quest to live positively.
- **Self-empowerment:** You must take control of your own destiny. Accept that you are accountable for your actions from this day forward. Take responsibility for your issues. Decide to seek help for yourself, your children, your family... commit to doing what ever it takes to keep yourself and those you love healthy.

A healthy body

People infected with HIV need to keep their body strong and healthy.

Protect & strengthen your body

- **Our bodies fight infection better when we keep up our energy. Things that affect our energy levels:**
 - Rest
 - Exercise
 - Diet

Resting

Resting is an important part of staying healthy.

- People with HIV should build rest into their daily routine – as needed.
- Allowing yourself to become overtly tired is not good for your body or your ability to stay healthy.
- This does not mean you should stop activities you enjoy & are still able to do – only that you should listen to your body.

exercise

Exercise Maintaining good fitness keeps us prepared for physical challenges.

- Exercise should be regular and moderate
- for example walking for 20 minutes a day & doing stretching exercises to keep our bodies flexible.
- A strong/fit person is better able to fight off infection and recover from illness

diet

Diet Maintaining a healthy balanced diet is critical to keep the HIV-positive person well.

- You do not have to eat expensive food
- Good nutrition is first **before** buying expensive herbal medications or immune boosters.
- A good diet is an excellent and essential means of providing what you need.

Nutrition & HIV

ENERGY for your body is provided by carbohydrates.
EXAMPLES: potatoes, millet, porridge, bread, rice
- you need some carbohydrates daily

BUILDING your body requires you to eat protein.
EXAMPLES: [beans + rice], fish, chicken, eggs, milk, yogurt, meat
- Muscles & immune cells (CD4) are made out of protein.
- Protein is the building blocks for new CD4 cells & your body
- You must eat protein every single day
- If you cannot afford meat/other protein, you must have [beans + rice] everyday

HEALING & GOOD FUNCTION fresh fruits & vegetables
EXAMPLES: spinach, paw-paw, butternut squash, oranges, apples, bananas, carrots, tomatoes, avoc, etc.
- Fresh fruits & vegetables are full of essential vitamins & minerals
- Note: Cabbage & filling, but does not provide much nutrition

you might want to avoid...

- **Hard food** - if you get diarrhea or upset stomach, it can be difficult to digest and can lead to excess gas (flat) rather than gaining muscle (good). Also, frying vegetables until they are limp, will destroy the vitamins & nutrients.
- **Sugar** - if you get oral thrush or have decayed teeth. Sugar encourages oral thrush to grow in your mouth. Brushing your teeth after every meal, especially after sweets is important. Sugar is also high in empty calories and so does not add to good nutrition.
- **Spicy food** - if you have stomach/ulcer pain. Spicy food can irritate the stomach and worsen gastritis and heartburn.

consider changes...

- **Try steaming or lightly boiling** instead of frying. This will leave more of the nutrients in the food.
- **Try eating your vegetables cooked only until they are still slightly crunchy or still firm & still have good color.** You can be sure the vitamins are still there!
- **Try drinking the water after cooking your vegetables** instead of throwing it out. A nutritious beverage full of free vitamins! Add salt and a little Roma.
- **Have beans + rice** everyday that you are not serving meat or chicken. Rice + beans together, provide very healthy and affordable protein. Remember protein should be eaten every day - not just the first days of the month when we have more money.

diarrhea

- Many germs are able to enter the body through food and cause gastroenteritis which is inflammation of the stomach that results in diarrhea.
- Watching what we put in our body is essential for HIV-positive persons. Both to **prevent gastroenteritis** and malnutrition - so we can maintain a strong immune system for as long as possible.
- Diarrhea can be very serious because it causes **dehydration** (lack of water) and imbalance in the electrolytes (salt and mineral) in the body.
- Diarrhea can be **very dangerous** and can even kill a person with advanced HIV/AIDS.

food safety

1. Fresh fruits/vegetables must be **washed in clean water**.
2. Keep **meat & vegetables separate** when preparing food.
3. **Raw meat, especially chicken skin, is covered with bacteria** which can get onto raw vegetable which we eat.
4. **Cook meat fully** to kill all bacteria and parasites.
5. **Do not ever eat raw meat or seafood!**
6. **Don't overcook green vegetables.** Cook only until they are firm. This way you preserve the protective vitamins.
7. **Try not to eat left over food** that has been out of room temperature (not refrigerated for more than a few hours). If it is older than a few hours, it is best if it can be refrigerated - and then fully re-heated before eating.
8. **Cooked food that is more than a day old** - may have become spoiled. Especially in the hot summer months - when food will spoil more quickly.
9. **Re-heating food that is already spoiled will not make it safe to eat. Spoiled food is loaded with bacteria** that can cause stomach upset and diarrhea.

fluid safety

- Sanitization & Hydration:** You need to drink 2 liters of clean water every day. More when you are sick. Water from a clean tap & collected in a clean container or boiled water is safe.
- Unclean Water:** Water from boreholes or rivers contains organisms such as bacteria, worms and parasites. These cause disease. Boiling or adding Ji will kill these organisms and prevent disease.
- Tea & Coffee:** contain caffeine which is a diuretic. This causes us to urinate more and lose water.
- Alcohol:** lowers the immune system. A small amount once per week can be ok, but more than that can be harmful. Excessive alcohol is extremely damaging to the liver and can lead to liver failure. *hey God if you want to take ARV!*
- Fruit Juice:** can cause stomach pain because it contains acid. *Fructose*. Buy 100% full juice with no added sugar. Juice drinks with lots of added sugar are low in nutritional value & not good value for your money. It is better to eat a piece of fruit instead of a sugary drink.

Immune boosters & herbal mixtures

- BEST IMMUNE BOOSTER:** In our case where money is a too little, good nutrition alone can be the best immune booster that we can buy.
- BASIC FOOD:** is cheaper and can be used by everybody in our homes instead of taking food money to buy something that only one person is eating.
- CHANGE OF LIFESTYLE:** Healthy eating, exercising and making time to rest and just little bit of change in our lifestyle - will help strengthen your immune system.

We must believe... our actions are our own

- Keep the focus where it belongs - on our own thoughts, emotions and actions.
- Stay in the present - in the here and now. Today you must begin.
- Once you believe that you have control over your life and that your actions define this life, you can begin to think of your challenges and problems in a new way.

laxatives, enemas & vomiting

- CULTURAL PRACTICES:** it is a common practice in our culture to use laxatives or enemas to "clean the stomach". This results in diarrhea. These should be avoided in the HIV-positive person, because it robs the body of water and upsets the electrolytes just as an infection will. Self-induced vomiting is also used to "remove bile".
- Positive persons must keep fluids up rather than taking them to GIT .
 - The body is an amazing creation that is capable of "self-cleaning" without the need for any help from laxatives or causing vomiting!
 - Laxatives and enemas should only be used by persons who suffer from acute constipation and in that case the laxatives & enemas should be prescribed and managed by a health care practitioner. Self-induced vomiting also results in fluid loss - as well as electrolyte imbalance. This can be very dangerous.
- CONSIDER** what OTHER cultural practices might be substituted that are acceptable & will cause less complications for your health.

Taking control & moving forward

Stop seeing yourself as a victim!

- It is easy to start feeling like a victim.
 - You think why did this happen to me?
 - You blame someone else for bring HIV into your life.
 - You think "who is the person who infected me"
- ↓
- This thinking will not help anyone!**
- It will bring you down & slow your path to positive living and survival.
 - You must be willing to let go of these thoughts & role of the victim.

then whose fault is it?

- There is **no need to blame** anyone for your HIV-status.
- There is a big difference between **blame & responsibility**.
- **Blaming a person to blame will not help anyone now.** (Examples: wife blaming husband, mother blaming her son, you blame yourself...)
- We must not blame → but instead **become accountable & responsible** for your own life from today forward.

The poet **Maya Angelou** said
"You did what you knew how to do,
and when you knew better, you did better"

Protect yourself

by adopting new sexual practices

- Find out the HIV status of your partner
- Encourage him/her to go for testing
- If they are hesitant, offer to go with them to testing
- If you start a new relationship, discuss HIV
- Why use condoms every time?
 - Protect yourself from re-infection with another strain of HIV
 - Protect yourself from STIs – these can allow HIV to get worse and spread more easily
 - Protect your partner from infection or re-infection

Ready or not

Do you have a condom with you right now?

- If not, you are not prepared to be safe!
- Don't expect your partner to take the lead
- If you are afraid to talk to your partner – or think he/she will refuse to use a condom – speak to your counsellor for advice.
- You are not only protecting yourself, but your partner too

Any questions?



- Is it easy to disclose to your partner?
- Is it easy to talk about HIV with a new partner?
- Is it easy to ask your partner to use a condom?
- Does anyone have a story to share?
- Suggestions on how to disclose/discuss condom use?

become a HEALTH SEEKER!

Once you accept you deserve life & good health

- No one will advocate for you better than yourself
- You must empower yourself
- Take steps to change from being a **RISK TAKER**
- To become a **HEALTH SEEKER**
- While the clinic staff is there to provide care
- Don't wait for anyone or expect anyone to bring treatment and care to you
- Become a health seeker & self-advocate!

CONCLUSION

You must take control now...

- Any choice you make → has consequences.
- If you make good or bad choices → the result will reflect that
- If you have negative or positive thoughts → the result will show
- If you choose thoughts filled with anger & bitterness → you will have an outcome that is full of alienation, hostility and isolation

The mind and body are linked.

- What your mind thinks → your body feels
- Negative thoughts and depression have a direct effect on your immune system.
- So it is essential that you keep your mind positive, so your body can be strong and help you fight off infection and HIV.
- Become a **HEALTH SEEKER!**

See you next week!

- You can bring a 'buddy' (or family member) to training
- Next week => Training Module 2
 - Basics of HIV
 - Transmission of HIV
 - Mother to child transmission
 - Introduction to ARVs
- If you cannot make it next week, tell staff today so they don't think you have disenrolled
- Remember, only person who complete training will qualify for ARVs!

Module 2 HIV Care & Treatment

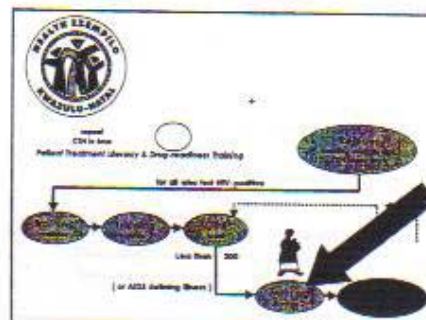
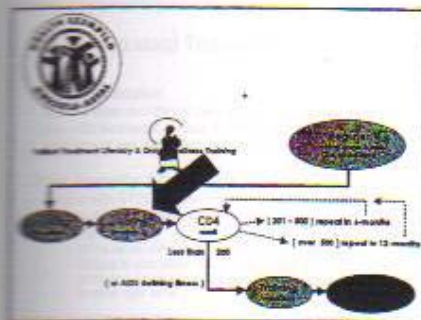
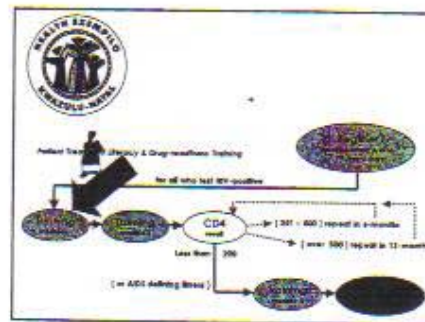
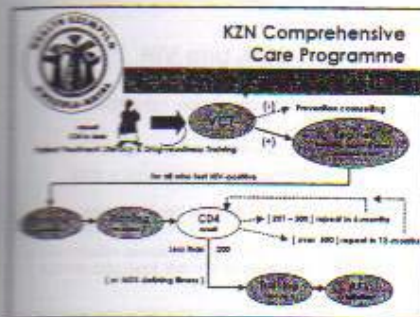
HIV basics
MTCT
OI treatment & prophylaxis
HIV Care & Treatment
Introduction to ARVs



KZN Department of Health
Patient Treatment Literacy

Welcome back...

- Did anyone disclose this week?
- Is there anyone who can share their disclosure story with the group?
- For persons who have not yet disclosed, what will help you to disclose at home?



To be covered today...

- Basics of HIV/AIDS
 - How is HIV spread
 - Mother-to-child transmission
 - Infant feeding
 - Testing for HIV
 - Window period
- Opportunistic infections
- Introduction to ARV drugs

Basics of HIV & AIDS

HIV and AIDS

- HIV & AIDS often used interchangeably
 - HIV* = *Human Immunodeficiency Virus*
 - AIDS* = *Acquired Immunodeficiency Syndrome*
- Being infected with HIV does not mean you automatically have AIDS
- HIV infection causes progressive damage to the immune system, over years, that over years will lead to AIDS

Transmission of HIV

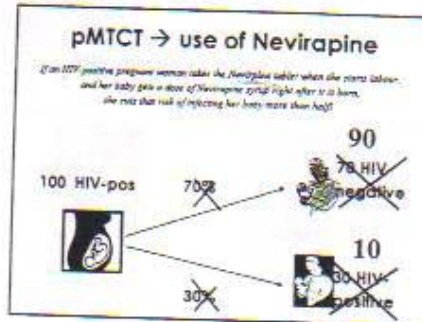
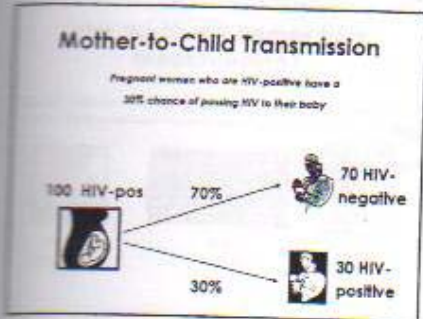
- **Where is HIV found in the body?**
 - Any body fluids:
semen, vaginal secretions, blood and breast milk
 - No transmission from
tears, saliva, urine, sweat
- **How is the HIV passed?**
 1. Sex with an infected person
 2. Blood - used needles, traditional scarification, cuts
 3. Mother to her baby (MTCT)

Sexual Transmission

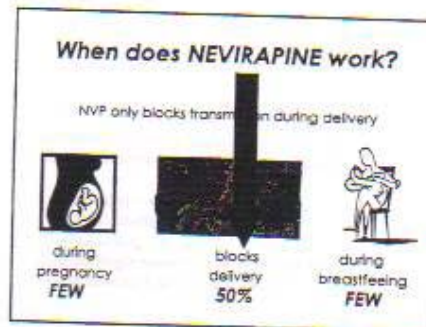
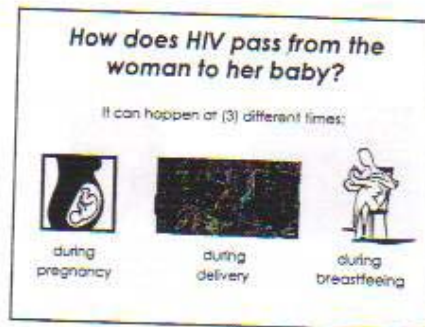
- HIV Transmission**
- Occurs when an HIV (+) person has unprotected sex
 - Sex with exchange of body fluids containing virus
 - All forms of sex can infect (oral, penis-vagina, anal)
- Other Sexually Transmitted Infections**
- People with STIs get infected with HIV more easily.
 - People with STIs pass the HIV more easily
- Why?**
- STIs cause inflammation and breaks in the skin
 - Breaks in skin allow HIV to enter more easily
 - STIs should be avoided if possible, and if contracted → treated right away

Blood Transmission

- Any activity that causes transfer of HIV-infected blood from one person to another can transmit the virus
 - sharing contaminated needles
 - sharing razor blades
 - sharing tattoo needles
 - traditional scarification of whole family
 - blood transfusion with infected blood
 - touching cut/blood of person infected




- ### Nevirapine for pMTCT
- Stigma prevents women from going for VCT
 - Pregnant women are at increased risk of having a positive baby - if they do not use NVP
 - Single dose NVP for women only protects the baby
 - It is proven to reduce the risk of HIV-transmission
 - It does not guarantee the baby will be negative
 - It does not treat the mother
 - Men take their partner's NVP because they don't understand - one dose will not help HIV infection!





How much risk comes from breastfeeding?

The risk can be minimal **if** you exclusively breastfeed for 6 months - without 'mixed feeding' (only breast milk)





during pregnancy during delivery during breastfeeding

what should an HIV-positive mom choose?

<h4>Exclusive bottle feeding</h4>  <p>ADVANTAGES</p> <ul style="list-style-type: none"> • no risk of passing HIV • other persons can can help with feeding 	<h4>Exclusive Breastfeeding</h4>  <p>ADVANTAGES</p> <ul style="list-style-type: none"> • complete nutrition for baby • affordable & convenient • low risk transmission if exclusive • no stigma
--	---

what should an HIV-positive mom choose?

<h4>Exclusive bottle feeding</h4>  <p>NEGATIVES</p> <ul style="list-style-type: none"> • expensive \$500/month • unsterilized water + formula can kill your baby • can have stigma 	<h4>Exclusive Breastfeeding</h4>  <p>NEGATIVES</p> <ul style="list-style-type: none"> • some risk of passing HIV • risk increase if mixed feeding • exclusive feeding can be a challenge
--	--

One will be best for you!

<h4>Exclusive bottle feeding</h4>  <p>CHOOSE if it is right for you!</p> <ul style="list-style-type: none"> • If you have an extra \$500/mo • If you don't mind getting up for night feedings • family is supportive, no stigma 	<h4>Exclusive Breastfeeding</h4>  <p>CHOOSE if it is right for you!</p> <ul style="list-style-type: none"> • If no formula at your clinic • If you don't have \$500/mo • If you don't have access to safe water all the time • If you will exclusively feed only
---	---

These do NOT pass HIV...

- HIV is not easily transmitted
- it can not be passed by...
 - Casual contact: working, swimming with HIV+person
 - Not passed on toilet seats, phones, share clothes/food
 - Friendly touch...hugs, kisses on cheek, sitting close
 - A mosquito bite
 - A bewitchment

These do NOT cure HIV...

- AIDS is caused by a virus infection.
- There is currently no cure for HIV/AIDS.
- It is a incorrect that HIV can be cured by...
 - Having sex with a virgin or a baby
 - Herbal medications
 - Antibiotics
 - Washing/cleansing genitals after sex
 - Doctors or Traditional healers

The CD4 cell & the Immune System

- Our immune system = like an ARMY
- CD4 cells = like soldiers
- The CD4 cells fight wars against any infection
- Immune system = different kinds cells (soldiers)
 - T-cells (CD4 cells)
 - B-cells (make antibodies)
- We need CD4 soldier cells to fight off infections
- If our CD4 cells are few, our immune system or army is weak

The Cycle of HIV-Infection

- HIV's main target is our body's CD4 T-cell
- HIV attaches to our CD4 cells - like lock-in-key
- Empties its contents or 'core' inside the CD4 cell
- Once inside, HIV hi-jacks the CD4 cell
- HIV forces the CD4 to make more virus
- Each infected CD4 cells acts like a factory for HIV
- Once a CD4 cell is infected, it doesn't work well
- The number of good CD4 cells falls & the immune system becomes weak

HIV-positive → to AIDS

- Right after infection, we have lots of CD4 cells
- As HIV infects more & more CD4 cells
- The infected cells make more & more HIV
- The number of HIV or our VIRAL LOAD goes up
- The number of CD4 cells goes down
 - The immune system (army) gets weaker & weaker
 - Immune system is weak or 'deficient'
 - *I m m u n o d e f i c i e n t*
 - Human Immunodeficiency Virus (HIV)

How does an HIV test work?

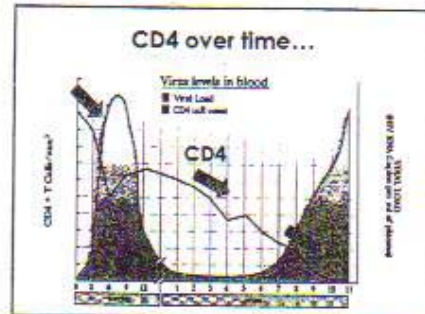
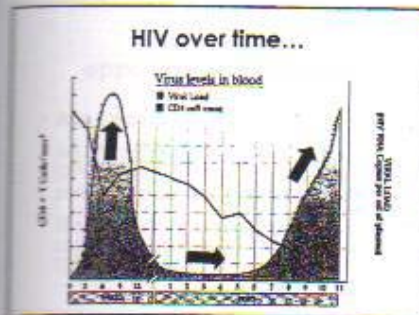
- HIV test: Doesn't test to see if the virus. It tests for antibodies we make to fight HIV.
- After infection → body makes antibodies
- For the first few months → there is only a small amount of antibodies
- The test for antibodies (or the HIV-test) cannot detect these antibodies initially → so a person can test negative while they ARE infected.

What is the window period?

- It takes about 3 months after HIV-infection, for the antibody test to be positive
- During the *window period*, a person will test negative...but is does have HIV in their body
- A person can very easily pass HIV during the *window period*!

Other tests for HIV-infection?

- Viral Load = measures how much virus is in the body. Allows you to monitor stage of infection.
- CD4 Count = how many CD4 cells in body. Lower CD4 count means your immune system is damaged.

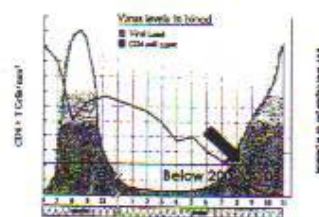


CD4 Count and sickness

Remember, CD4 cells direct immune response

- CD4 count gets low → *sick*
- Normal CD4 count is over 500
- CD4 count is below 200 → '*AIDS*'

CD4 below 200 = AIDS



Summary

- HIV infection progresses over time to AIDS
- HIV is spread by
 - (1) Sex
 - (2) Blood
 - (3) (3) mother to child
- Nevirapine reduces mother-to-child transmission
- HIV damages our immune system
- HIV lowers our CD4 cells
- HIV replicates in CD4 cells & viral load increases

HIV-Associated Opportunistic Infections

What is an opportunistic infection?

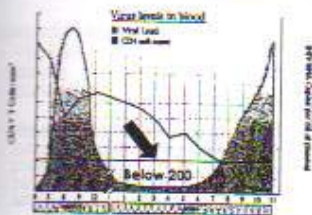
- Also called OI
- An infection or illness that takes the OPPORTUNITY to cause an illness in a person who is immunocompromised
- Opportunistic infections are more common in persons who have a lower CD4 count

Early treatment

Remember...

- HIV doesn't kill → OI's kill
- Most OIs are treatable/curable
- Some are preventable
- Early treatment for OIs prolongs life!

OIs start after CD4 less than 200



Can you name some OIs...

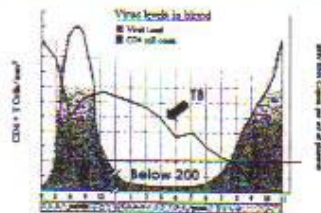
- TB
- Oral thrush
- Esophageal thrush
- Cryptococcal meningitis
- Pneumonia - bacteria
- Pneumonia - PCP
- Kaposi Sarcoma
- Lymphoma
- Diarrhea - longer than 4 wks
- HIV wasting
- Cervical cancer

which OI kills the most?



- TB is the #1 killer of HIV-positive persons.
- TB is treatable
- You must go for evaluation as soon as you develop a cough – to make sure it is not TB

TB can come at any CD4 count



Is a cough serious?

- A cough that won't go away or cough with fever - could be serious
- It could be PCP or TB or pneumonia
- If these are not treated, they can kill you
- Do not wait until you are very sick!
- Take all of your medicines for the cough, even if you start feeling better
- Finish all tablets!
- If you have finished your tablets and are still coughing - go back to the clinic right away!

TB

- TB is a common opportunistic infection
- It is the #1 killer of HIV-infected persons in South Africa
- **Main symptoms:** cough, night sweats, weight loss, chest pain, fever, fatigue.
- **What do you do?** Tell the clinic if you are having these symptoms. They will collect sputum & check for TB.
- **How is it treated?** You will have to take tablets every Monday - Friday for 6 months
- **Can I get TB more than once?** Yes. If you develop a cough, always have it checked at the clinic!

PCP

- Pneumocystis carinii pneumonia
- Can be very serious if left untreated
- **Symptoms:** fever, dry cough,
- **Other:** chest tightness, difficulty breathing, out of breath when you walk, fever, tired.
- **What should you do?** Tell the doctor if you are having these symptoms
- **Can it be treated?** Yes. With Bactrim
- **Can I get PCP if I am taking Bactrim?** If you miss doses - your risk is increased. If you take Bactrim everyday as instructed, your risk is less.

Other cough

- This is pneumonia (like TB & PCP) caused by bacteria
- It is common for HIV+ persons to get this
- **Symptoms:** cough, sputum, fever, chest pain
- **What must I do?** Tell the clinic if you are having these symptoms.
- **How is it treated?** The doctor will prescribe antibiotic tablets for you. Be sure to finish all of the tablets you are given. If your symptoms do not get better, return to the clinic. It is possible you have more than one infection.
- **Hospital:** Don't wait at home until you are very sick. If you do this, you may need to be admitted to hospital

What if you have a headache?

- A headache that lasts more than a week or if it is very bad and different than other headaches you've had - it might be serious.
- It could be meningitis
- Meningitis is an infection around the brain
- If meningitis is not treated, it will kill you
- Do not wait until you are very sick!
- If you have a new headache that won't go away, go to the clinic!

Other Meningitis

- Serious infection around the brain
- Caused by bacteria or virus
- **Symptoms:** same as cryptococcal meningitis
- **What must you do?** If you have a severe headache, do not wait. Go immediately to the clinic or hospital.
- **What is the treatment?** Depends on the kind of meningitis you have. There is no prophylaxis for OTHER MENINGITIS

Oral Thrush



- Infection in the mouth
- If it spreads to the throat → esophageal thrush
- Caused by a fungus
- Can also cause infection in vagina
- **Symptoms:** white patches in mouth, sore mouth, sore throat, nausea, loss of appetite
- **Treatment:** nystatin lozenges, perssaries, nystatin mouthwash
- **Prevention:** good oral hygiene. Brush teeth and rinse mouth after eating – especially after sweets.

What if you have pain or trouble swallowing?

- This might be an infection
- It could be thrush that has spread down your throat
- Persons who have trouble swallowing might avoid eating
- It is essential that HIV-positive persons do not avoid eating or having good nutrition
- If you have trouble swallowing, do not wait.
- Go to the clinic see if you need treatment for thrush in your throat.
- Thrush in your throat is called....

Oesophageal Thrush



- Caused by a thrush spread from your mouth to your throat or oesophagus

- **Symptoms:** pain when swallowing
- **Treatment:** Diflucan
- **DANGER:** if you don't eat due to pain → can lead to malnourishment

Thick white candidal plaques are seen, with bleeding of surrounding mucosa due to extreme irritability of the inflamed oesophagus.

Herpes



- Viral infection that causing ulcers/sores
- It can be on the Mouth/lips, genital, rectum area
- Once you have herpes - you have it for life! No cure.
- Your herpes ulcers or outbreaks will come & go - can be very painful
- **PREVENTION:** condom all the time.
- **REDUCE RECURRENCE:** Outbreaks happen more often when if we are stressed or very tired → so stress reduction & positive living are important ways to reduce your outbreaks.
- **TREATMENT:** There is no cure - but if you start ACICLOVIR tablets within 2 days of an outbreak, the ulcers may resolve sooner and be less painful.
- **CARE:** avoid sex during outbreaks, use condoms all the time to prevent passing HERPES to your partner.
- Can be passed mother to child during birth.
- Discuss with doctor if you have genital herpes and & pregnant!

Other STDs...

Can be seen in HIV-negative & positive

- Gonorrhoea
- Chlamydia
- Syphilis
- Trichomonas
- Genital warts

REMEMBER: If you are having STDs, you are not using condoms properly & may be spreading HIV and/or getting re-infected with HIV.

Skin infections

- Skin problems are very common in HIV
- Not usually serious. Some are treatable.

Fungal infection of nail



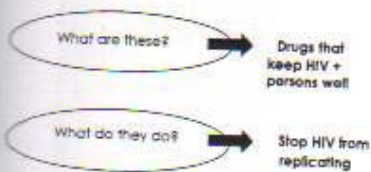
What is Care & Treatment for HIV/AIDS?

- Care & treatment is essential for good health in an HIV-positive person.
- Anti-retroviral (ARV) drugs are *only one part* of the treatment needed by an HIV-positive person.

HIV care & treatment

- **POSITIVE LIVING**
 - positive attitude
 - combining stigma + disclosure
 - good nutrition
 - exercise
- **SUPPORT**
 - family
 - church
 - grants
 - counselor
 - support group
 - education
 - clinic staff (doc/nurse)
 - friends
 - income/employment
- **PROPHYLAXIS FOR OPPORTUNISTIC INFECTIONS**
 - Zidovudine (to prevent PCP pneumonia)
 - Zalcitabine (to prevent toxoplasmosis)
 - Rucaparib (to prevent cryptococcal meningitis)
- **TREATMENT FOR OPPORTUNISTIC INFECTIONS**
 - Antibiotics
 - pain meds
 - antifungals/antiparasite
- **REGULAR CLINIC VISITS**

Anti-retrovirals (ARV's)



HAART

- H = Highly
- A = Active
- A = Anti-
- R = Retroviral
- T = Therapy

3 or more ARVs. Only recommended ARV treatment – for long term effect.

how many ARVs do you need?

3

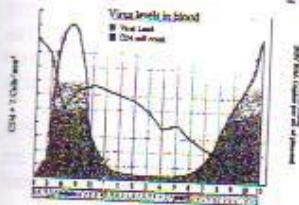
Remember how HIV attacks...

- HIV attacks the CD4 cells (generals of the army)
- Hi-jacks the CD4 cell
- Forces the CD4 become a factory for more HIV
- The CD4 cells can no longer fight infection

HIV → enters CD4 → more HIV → enters more CD4

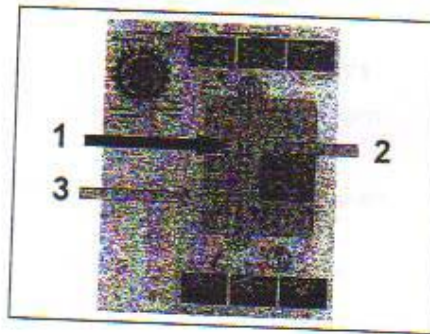
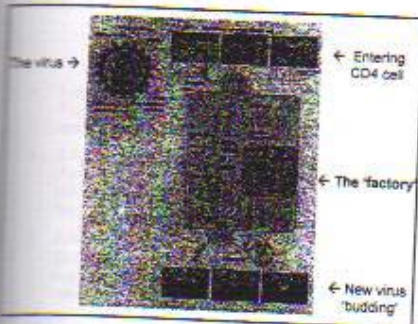
VIRAL LOAD ↑ (up up up) CD4 COUNT ↓ (down down down)

CD4 & Viral load over time...



What makes ARVs work?

- Function of ARVs → suppress viral replication
→ block steps in the factory
- No virus replication → Immune system recovers
- Immune system recovery means → CD4 count goes up
- CD4 count up → no more opportunistic infections



What makes ARVs work?

- Function of ARVs → suppress viral replication
→ blocks steps in the factory
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- Immune system recovery means → CD4 count goes up
- CD4 count up → no more opportunistic infections

ARVs = lots of different names

Common name	Research or brand name
• AZT	Zidovudine, retrovir
• ddI	Zalcitabine, stavudine
• ddC	Efavirenz, lamivudine
• Efavirenz	Virex, abacavine
• Nevirapine	Sustiva, Stocrin
• Tenofovir	Viread
• Indinavir	Crivarin
• Nelfinavir	Viracept
• Lopinavir / ritonavir	Kaletra

ARVs to be used in South Africa

- 3TC (lamivudine)
- d4T (stavudine)
- Nevirapine (Viramune)
- Stocrin (efavirenz)

- AZT (zidovudine)
- ddI (Videx)
- Kaletra (lopinavir & ritonavir together)

Choosing a combination

Why 3 drugs?

- **1 ARV (monotherapy)**
If you take only 1 ARV, your HIV will become resistant and the drugs will stop working
- **2 ARVs (dual therapy)**
If you take 2 ARVs, you will be well for a little while but eventually your HIV will become resistant and the drugs will stop working
- **3 ARV DRUGS (triple therapy)**
Only by taking 3 ARVs – will the HIV stay suppressed for a long time – and not become resistant. 3 drugs will prolong life!

3 categories of ARVs

1. Nucleoside RT inhibitors NRTI
2. Non-nucleoside RT inhibitors NNRTI
3. Protease Inhibitors PI

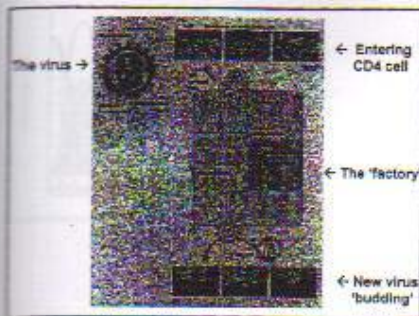
Which ARVs in which category

1. Nucleoside RT Inhibitors NRTI
3TC, d4T, AZT, ddI
2. Non-nucleoside RT inhibitors NNRTI
Nevirapine, Stocrin
3. Protease Inhibitors PI
Kaletra (lopinavir + ritonavir)

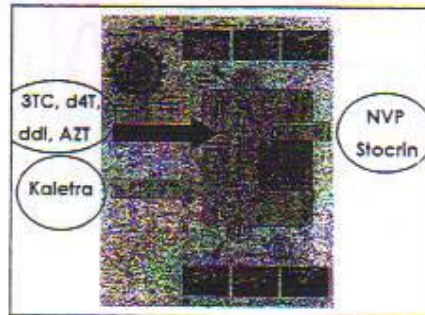
Blocking HIV replication

- Each category of ARV blocks HIV in a different place
- Let's see where the ARVs block HIV....

CD4 falls over time...



On ARVs viral load drops quickly



On ARVs...

What is a REGIMEN?

REGIMEN = a combination of ARVs

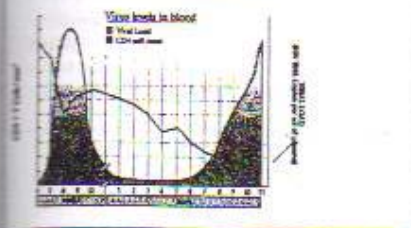
The SA government ARV programme will offer 2 different 'REGIMENS' or 'LINES'

- A first-line regimen (combination of 3 ARVs)
- A second-line regimen (or combination of 3 ARVs)

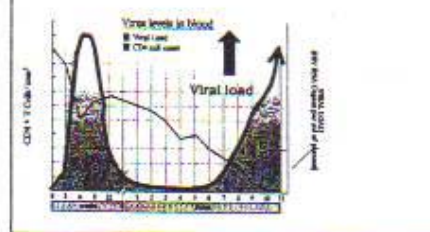
Why more than 1 REGIMEN?

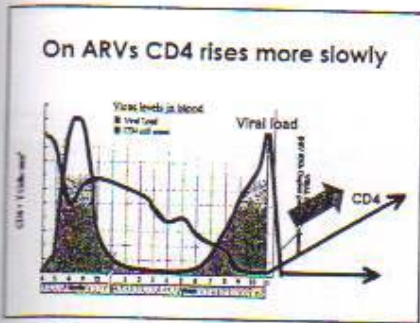
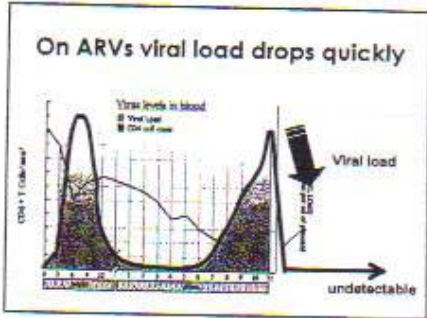
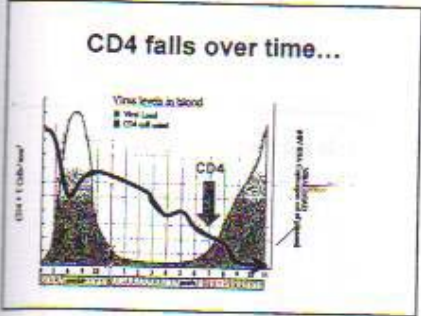
- Almost all patients in SA will be started on REGIMEN 1 = (3TC + d4T + NVP/or STN)
- It is an easy combination for most people
- Why is there a 2nd line or REGIMEN 2?
 - For patients who are non-adherent on REGIMEN 1 & develop resistance → first-line stops working
 - Also for patients who are allergic or cannot take REGIMEN 1 for any reason

Viral load & CD4 count without ARVs



VL increases over time...





**Starting
 ARV
 Treatment**

ARVs - who & when?

WHO?

- HIV-positive men
- HIV-positive women
- HIV-positive pregnant women
- HIV-positive children

WHEN?

- CD4 below 200
- Or AIDS defining illness

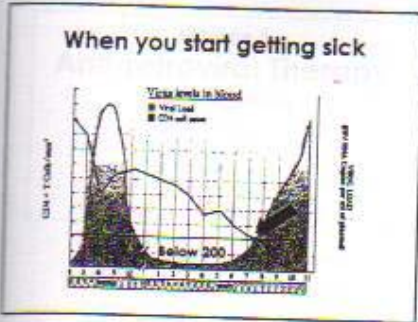
Why CD4 below 200?

WHO?

- HIV-positive men
- HIV-positive women
- HIV-positive pregnant women
- HIV-positive children

WHEN?

- CD4 below 200
- Or AIDS defining illness



What is an AIDS-defining illness?

WHO?

- HIV-positive men
- HIV-positive women
- HIV-positive pregnant women
- HIV-positive children

WHEN?

- CD4 below 200
- Or AIDS defining illness



Conclusion

- ARVs are only 1 part of treatment for HIV/AIDS
- Treatment also includes counselling, good nutrition, OI prophylaxis (BACTRIM), treatment for TB, STIs, OIs
- ARVs are only needed when the CD4 < 200 or AIDS defining illness
- You must take a combination of 3 different ARVs
- A 3-drug REGIMEN will
 - lower HIV viral load
 - increase your CD4 count
 - lengthen your life
- ARV treatment is for the rest of your life

your next visit...

- If your CD4 count is over 200, make sure you have an appointment in 6 months to repeat it. You don't need ARVs now & won't need any more training at this time.
- If your CD4 count is below 200, you will be coming next week for training module 3
- Remember, you can bring a friend to training.
- If you cannot make it next week, tell staff today so they don't think you have disenrolled
- Remember, only person who complete training will qualify for ARVs!

Module 3
Anti-retroviral Therapy

Drug Regimens
Adherence
Side-effects
Resistance
Monitoring
Making a Treatment Plan

 KZN Department of Health
Patient Treatment Literacy

welcome back!

QUESTIONS

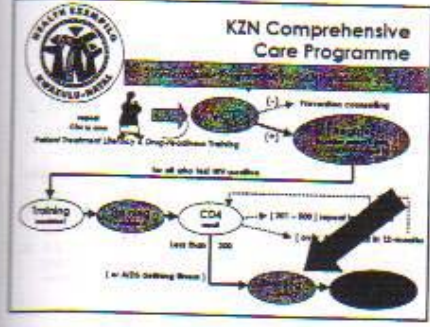
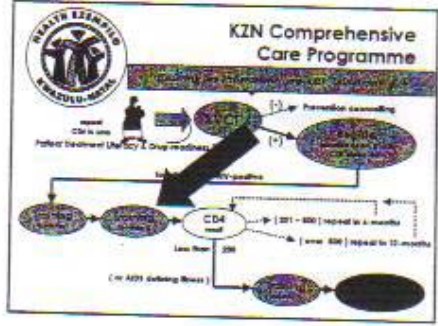
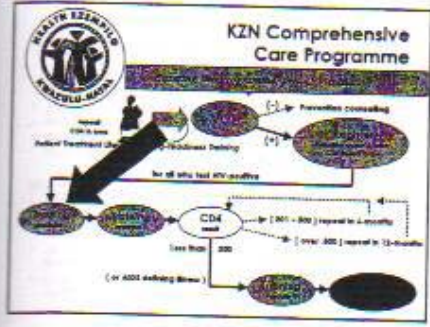
- Any questions from last week?

BACTRIM

- Is everyone taking BACTRIM?
- Any problems with your BACTRIM?

DISCLOSURE

- Has anyone disclosed since last week?
 - Would you like to share your story with the group?







Topics to be covered

- Drugs for the KZN ARV programme
- Adherence
- ARV side-effects
- ARV Resistance
- Laboratory monitoring
- Making a treatment plan

Your ARV Regimen

Two first-line regimens

- | | |
|--|--|
| 1. 3TC  | 1. 3TC  |
| 2. d4T | 2. d4T |
| 3. Stocrin  | 3. NVP  |

Who will get Regimen 1a? [3TC + d4T + Stocrin]

- **MEN** - all adult & adolescent
- **WOMEN** - post-menopausal women
- **WOMEN** - or women who have had tubal ligation or hysterectomy

WHY?

- Regimen 1a is safe & effective
- But, 1a contains Stocrin, which can cause birth defects.
- So all adult men & women will take this regimen, except for women who might fall pregnant.
- All women who could have a baby - will be started on Regimen 1b (NVP instead of Stocrin)

Regimen 1a

3rd drug = Stocrin

- | | | | |
|----------------|---|---|---|
| MORNING |  |  |  |
| | d4T | 3TC | Bactrim |
| EVENING |  |  | |
| | d4T | 3TC | |
| BEDTIME |  |  |  |
| | | | Stocrin |

Who will get Regimen 1b?

[3TC + d4T + NVP]

- **WOMEN** who can fall pregnant (child bearing potential)
- **ANYONE** (men or women) not able to take regimen 1a
 - Persons on shift work (avoid Stocrin/1a, if makes you tired)
 - Persons who work night duty (avoid Stocrin/1a, makes you tired)
 - Persons who have serious clinical depression (avoid Stocrin/1a, it can make depression worse)

WHY?

1. Regimen 1b is also safe and effective.
2. It does not contain Stocrin - so is safe for women because it has no risk of causing birth defects.
3. It is also a good regimen for persons who are on night or shift duties at work, because it does not contain Stocrin which can make you too tired to work night duty.

Regimen 1b

3rd drug = NVP

- | | | | |
|----------------|---|---|---|
| MORNING |  |  |  |
| | d4T | 3TC | NVP |
| |  |  |  |
| | | | Bactrim |
| EVENING |  |  |  |
| | d4T | 3TC | NVP |

?

Does everyone know which they will be taking?

or

- all men
- post-menopausal women
- women with tubal ligation/ hysterectomy

or

- all women of child-bearing potential
- men or women – shift workers/night duty
- clinical depression / prior suicide attempt

Details of first-line drugs...

	d4T	Larger dose (40mg) if weight more 60kg <u>MAIN SIDE-EFFECTS:</u> peripheral neuropathy
	3TC	Very well tolerated
	NVP	Start 1 daily for first 14 days, then 2x/day <u>MAIN SIDE EFFECTS:</u> rash & liver toxicity
	Stocrin	Taken at bedtime because causes sleepiness <u>MAIN SIDE EFFECTS:</u> rash & liver toxicity, vivid dreams, birth defects if taken in pregnancy

What about Regimen 2?

- Almost every person in KZN will be able to take either regimen 1a or 1b
- Who is regimen 2 for?
 - Persons who have side-effects and must stop taking regimen 1a or 1b
 - Persons who FAIL regimen 1a or 1b
 - You can FAIL regimen 1a or 1b if you are non-adherence

Regimen 2

3rd drug = protease inhibitor

MORNING	 AZT	 ddl	 Kaletra
			 Bactrim
EVENING	 AZT	 ddl	 Kaletra

Details of second-line drugs

AZT		DOSE: 1 tab twice daily EARLY COMPLAINTS: Insomnia, headache, nausea MAIN SIDE EFFECT: anemia
ddl		DOSE: 1 tab twice daily Take on empty stomach (30-min before or 2-hr after meal) MAIN SIDE-EFFECT: peripheral neuropathy, nausea, diarrhea
Kaletra		DOSE: 3 capsules twice daily Take with food: add 300mg Abacavir if starting TB treatment; take in fridge (stable 3mo @ room temp) MAIN SIDE EFFECTS: dizziness, nausea, liver toxicity LONG-TERM SIDE EFFECTS: Spodystrophy, insulin resistance, cholesterol abnormalities

What if I do fail both regimens?

- You will have very few options at this time
- It is critical for you to adhere 100%
- Stay on REGIMEN 1 for as long as possible!
- Once you have to switch to REGIMEN 2, there are no more options after that

Adherence

what is adherence?

Taking drugs exactly as prescribed

- On time
- Following any dietary restriction
- No missed doses

why is adherence so important?

Taking drugs exactly as prescribed

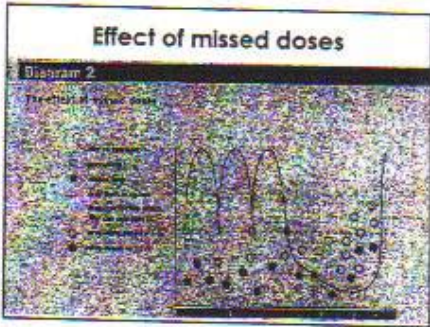
- On time → → → → → good drug level
- Following any dietary restriction → good absorption
- No missed doses → → → → → good drug level

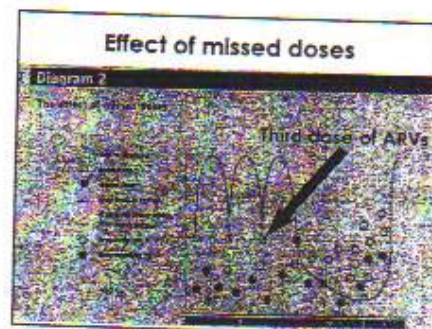
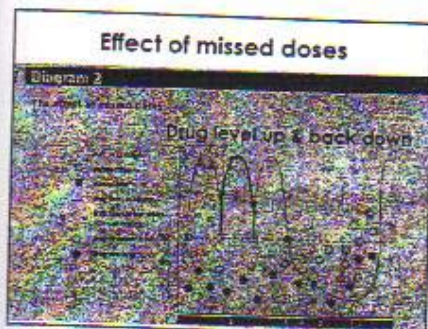
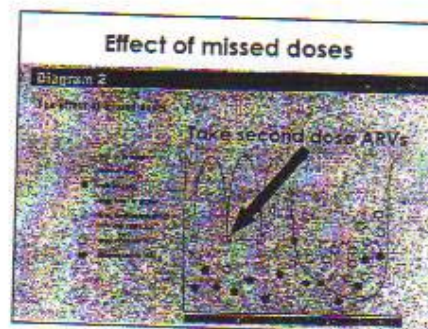
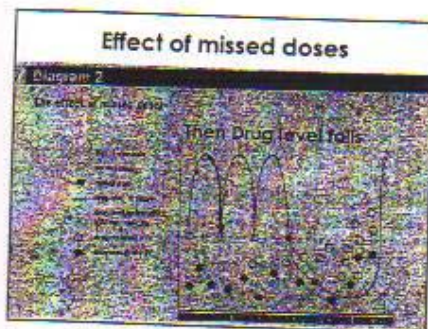
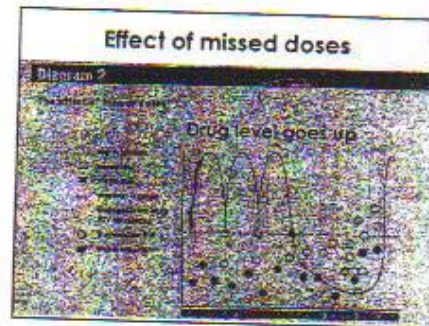
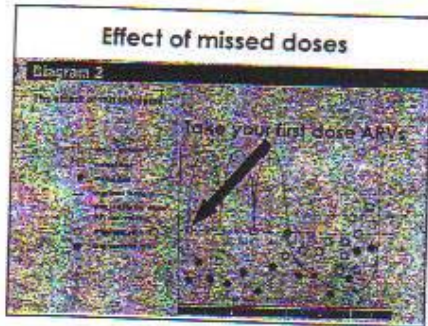
what happens if non-adherent?

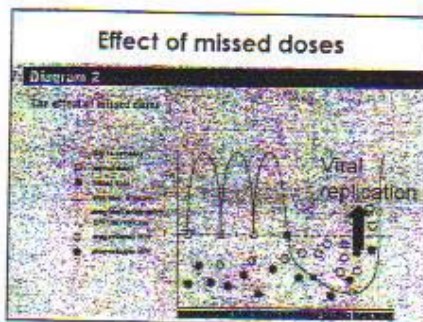
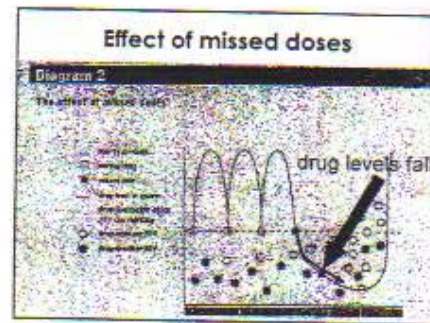
~~Taking drugs exactly as prescribed~~

- ~~• On time → → → → → good drug level~~
- ~~• Following dietary restriction → good absorption~~
- ~~• No missed doses → → → → → good drug level~~

Increased viral replication & drug resistance !







- ### Failure to adhere
- Missing even a few doses can cause HIV to become *resistant*
 - Resistant HIV → ARV failure
 - ARV failure → viral load ↑ + CD4 ↓
 - 90-95% adherence mandatory

- ### What must you do to adhere?
- Give yourself time to get used to the ARVs
 - Prepare mentally for the side effects
 - Develop a routine...work ARVs into your routine
 - Near toothbrush
 - Near bed-head
 - In work bag
 - Develop good practices
 - Take meds with you on day outings
 - Take meds with you for weekends
 - Never run out of supply at home
 - Seek & accept support

- ### Adherence tools
- Anything that can help you adhere = 'tool'
 - Pill boxes – standard
 - Stickers / calendars – pictures of pills
 - Pill boxes with alarms / computer chips
 - Set alarm-watch
 - Friends to phone reminders
 - Adherence 'buddy' or partner
 - Therapeutic counselor (home monitor)
 - Pill counts
 - Self report

ARV adherence & side effects

- Side-effects can make adherence difficult
- Most are mild & and short lived
- If side-effects are affecting adherence
→ you must tell your doctor or other clinic staff.

ARV side-effects

What is a drug side-effect?

Unintended effect on the body

- Any drug can have side-effect
 - Examples: Paracetamol, penicillin, TB medications, etc.
- Most ARVs do have side-effects
- Most ARV side-effects are mild
- Most will stop after 4-6 weeks
- There it is rare to have serious side-effects

Will everyone have ARV side-effects?

- No, not every person will have ARV side-effects
- We cannot predict who will have side-effects
- But most people will have experience some
- You must learn
 - what side-effects you might have
 - When they will start
 - How long they will last
 - Which ones might be serious
 - What to do if you have a side-effect

things you might feel

Tired

- Some people say they feel tired after starting ARVs
- You can also have some trouble concentrating
- This can start in the first few days
- It might last for a few days or weeks
- You must give your body time to get used to ARVs

Diarrhea

- Some people may have diarrhea with ARVs
- Kaletra (2nd line ARV) is the most common drugs to cause diarrhea
- It is less common with the other ARVs
- Diarrhea may also be due to an infection – instead of your ARVs



Numbness or burning

- ARVs can cause numbness or burning in feet or hands
- This is called *PERIPHERAL NEUROPATHY*
- It is caused by the ARVs called d4T & ddI
- It is usually worse at night
- Sometimes it goes away
- If you experience this, you must tell your doctor
- There are medicines to reduce the discomfort
- If it becomes very painful & does not better with treatment, your doctor might have to change your ARVs

Fever

- Some side-effects can also have fever – like rash
- A fever can be a side-effect or it might be an infection

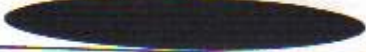


what if they don't go away?

- Side-effects that don't stop on their own, can be treated
 - Nausea → anti-emetics / home remedies
 - Rash → steroid cream / anti-histamines
 - Feeling tired → take dose near bedtime
 - Loss of appetite → small frequent meals
 - Tingling/burning in feet or hands → medications
- Report all side-effects to the clinic

what if they don't go away?

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ARV Resistance

What is resistance?

When the HIV changes & ARVs stop working

- ARVs slow down the replication of HIV
- If taken exactly as instructed, the viral load will drop & become undetectable
- If there is too little drug (ARV) in the body, then the virus can replicate
- If the level of drug (ARV) stays low, the replicating virus will become **RESISTANT**
- Once the HIV becomes resistant, ARVs no longer work and the virus will replicate and viral load will go up

What causes resistance?

Main reason for resistance is non-adherence

- Missing doses means too little ARV in the blood
- Lower levels of ARV in the blood allows HIV replication
- More resistant HIV is made
- ARVs can't stop resistant HIV, so they stop working
- Viral load goes up → CD4 goes down

Avoiding resistance

Strict adherence

- If serious side-effects occur, your doctor will decide which drug(s) should be changed or stopped
- One ARV might be changed, but you will always take 3-drugs
- If you are having trouble adhering for ANY reason, you must talk to the clinic staff
- Your clinic should support you as part of a partnership – but the commitment is yours!

Infection with drug-resistant HIV

- People can become infected with a drug-resistant strains of HIV
- This occurs if they are infected by a person who has taken ARVs → been non-adherent → developed resistant virus.
- Once your HIV is resistant, your treatment options become limited

Protect yourself

- It is critical for you to protect yourself and practice 'positive living'
- This means embracing the opportunity you are being given (access to treatment) allowing you to become healthy and live a full life
- You must protect yourself through safe sexual practices (so you don't become re-infected)
- You must protect others from becoming infected by you as well.

Monitoring

Why do I have to come back to the clinic so often?

Why does the clinic take my blood?

Clinical Monitoring

Looking for signs or symptoms of drug side-effects (rash, nausea, headache, etc)

- Done at the clinic by doctor and/or nurse
- Done at home by the patient
- Done at home by the home-based carer

Why are the blood tests for?

1. Baseline (before ARVs)

- check your immune system (CD4 count)
- how much virus is in your body (viral load)
- whether it is safe to give you ARVs (liver & kidney function)

2. Monitoring (after starting ARVs)

- Make sure drugs are not harming your body (side effects)
- Check to be sure the ARVs are working (viral load is undetectable at 6 months & CD4 is going up)

CD4 count

Measures the number of CD4 cells in blood & tells you how strong your immune system is

- This was checked at baseline when you enrolled
- Your first re-check will be at 6-months
- If you are adherent to your ARVs, you should see an good increase in your CD4 count
- It is possible your CD4 count will rise above 200 in the first 6-months or 1-year on ARVs
- Once your CD4 count is above 200 for 6 months, you can stop taking Bedtrim

Viral Load

Measures the amount of HIV in the blood

- This was checked at baseline when you enrolled
- It will be re-checked at 6-months on ARVs
- The Viral Load rapidly if you are adherent to your ARVs
- By 6-months you should be 'undetectable'
- 'Undetectable' = too little virus to be seen by the test, but the virus is still in your body
- If you become non-adherent, the VIRAL LOAD will increase again
- If you stop taking ARVs, the VIRAL LOAD will go up rapidly
- It is essential that you stay adherent you become and stay undetectable!

Other lab tests

- If you are on regimen 1a, it is very safe and you will not need a blood test until your 6 month viral load
- If you are on regimen 1b, you will be taking NVP which can cause harm to the liver.
 - You will have a blood tests at 2 weeks, 4 weeks & 8 weeks to be sure the Nevirapine is not causing harm to the liver

Making a Treatment Plan

Your body may be ready... sick & CD4 less than 200

but are you ready?

Personal Commitment (if/along)

Personal Readiness

- Disclosure to key persons for support
- Knowledge about HIV & ARVs
- Resources for food & transport (disability grant, employed)
- Joining a support group

Clinical readiness

- No cough or TB symptoms (or finished 2 months TB drugs)
- Taking Isotrim daily without problems

Making a treatment plan

- Treatment plan ← patient & clinic staff
- Personal situation
 - Partner/family support
 - Employment?
 - Enough food at home?
 - Stress?
 - Responsibilities (children)?
 - Transport?
- Lifestyle
 - Wake-up
 - Meal times
 - Bedtime
- Return to clinic & monitoring schedule
- Home visits / support

Treatment Plan

Each of you must help make your plan for how you will
take your ARVs

Designed by YOU (with help from the clinic staff)

It is based on YOUR lifestyle

YOU must be realistic and consider all of the factors that
will help...and hinder your adherence to ARVs

Treatment Plan - information

- Your ARVs are taken 12 hours apart
- Example: 7am & 7pm
- You must not choose a time when you are busy with other
responsibilities or distracted (feeding baby, on taxi, sleeping)
- If you are going to take STOCRIN (regimen 1a) you will have to
choose a time ~ 30 minutes before you usually go to sleep.
- You choose the time when you can always take them. Like when
you wake up. Consider what you are doing at the afternoon time.
- You must choose what tools you are going to use: cell phone,
alarm clock, bathbrush, television show. Before transport to work,
family member or buddy to remind you, etc.
- It is wise to tell your friends/family what times you chose so they
help remind you

Treatment Plan – more to decide

Where will you keep your ARVs?

Is it okay to put up a calendar at home to remind you?

What will you store your ARV's in?

What will you carry your ARV's in if you go out?

Who will you tell about your ARV's?

Where will you be when you take them?

(home, work, neighbors, etc)

How will you call the clinic/doctor if you have

questions or problems?

Where will you keep the clinic and counselor phone

numbers?

What will you do if you have a side-effect?

What transport will you use to get to the hospital if you

have a problem at night or on the weekend

Your Treatment Plan

Before you leave the clinic today

- Choose the times you will take your ARVs
- Make a calendar or tick list
- Review your plan with the counselor
- If you make any changes to your plan in the
future – discuss it with the clinic staff (counselor,
nurse or doctor)
- Discuss any concerns you have with the staff
 - Disability or child-care grant application
 - Disclosure
 - Sickness today – see the doctor
 - Using traditional medicines
 - Isotrim or TB medication

Conclusion

- ARV treatment is lifelong
- ARVs have side-effects which are tolerable
- ARV treatment requires a commitment from you
- It is a partnership between you and the clinic staff
- It requires that you are knowledgeable about ARVs
- It requires a support network – family, community
- Disclosure is very important to adherence
- Adherence is mandatory for treatment to work
- *There are some risks, but the benefit is life!*

**APPENDIX I: PSYCHOSOCIAL ASSESSMENT FORM USED BY
SOCIAL WORKER DURING THE INTERACTIVE SESSION**



DEPARTMENT OF HEALTH

**PROVINCE OF KWAZULU-NATAL
SOCIAL WORK DEPARTMENT
STANGER HOSPITAL
Private Bag X 10609
STANGER 4450
Tel.: 032 437 6038**

PSYCHOSOCIAL ASSESSMENT FORM

(Adults)

1. Identifying Details

Name _____

Surname _____

Physical Address _____

Postal Address _____

Nearest clinic _____

Nearest school _____

Nearest church _____

Nearest bus stop _____

Nearest shop _____

Name of street _____

Contact no. (Home) _____

Cell phone _____

Work _____

2. Family background/ support

Patient resides with _____

Contact no. _____

3. Financial background

Patient employed / unemployed _____

Occupation _____

Source Income _____

4. Educational background

Matric _____

Tertiary _____

Other _____

No. of children	Age	Status	Type of grant received

Religious beliefs _____

Reason for testing _____

Disclosure:

 Y N

To whom _____

Problems

 Y N

Is partner aware of status?

 Y N

Has your partner tested?

 Y N

Reason _____

5. Social Support system available in the community

Name: _____

Occupation: _____

How?: _____

UMnyango wezempilo, Departement van Gesondheid
Fighting Disease, Fighting Poverty, Giving Hope

Other: _____

Social grants

6. Socio-economic status

Electricity Y N

Surface water Pipe water Communal tap

Flushing toilet Y N

Transport: Taxi Bus Train Own

7. Lifestyle

If stopped

Do you smoke? _____ How long? _____

Do you take alcohol? _____ How long? _____

Do you take drugs? _____ How long? _____

Do you have a partner? Y N

Do you plan to have in future? Y N

Are you sexually active? Y N

Type of contraceptive in use _____

Recommendations:

DEPARTMENT OF HEALTH

Social Worker's Recommendations:

Grant: _____

Reasons: _____

Treatment: _____

Reasons: _____

DECLARATION

Patient

I _____ do understand and agree that the above information was given by me and it is true.

Patient's Signature

Date

Social Worker

I as a social worker do understand and agree that all information given to me by this patient / client will be treated with confidentiality.

Social Worker Signature

Date

UMnyango wezempilo, Departement van Gesondheid
Fighting Disease, Fighting Poverty, Giving Hope

**APPENDIX F: PHARMACIST ASSISTANTS NOTES FOR ARV DRUG
WORKSHOP, GROUP LECTURE SESSION**



**STANGER HOSPITAL
PHARMACY DEPT - ARV**

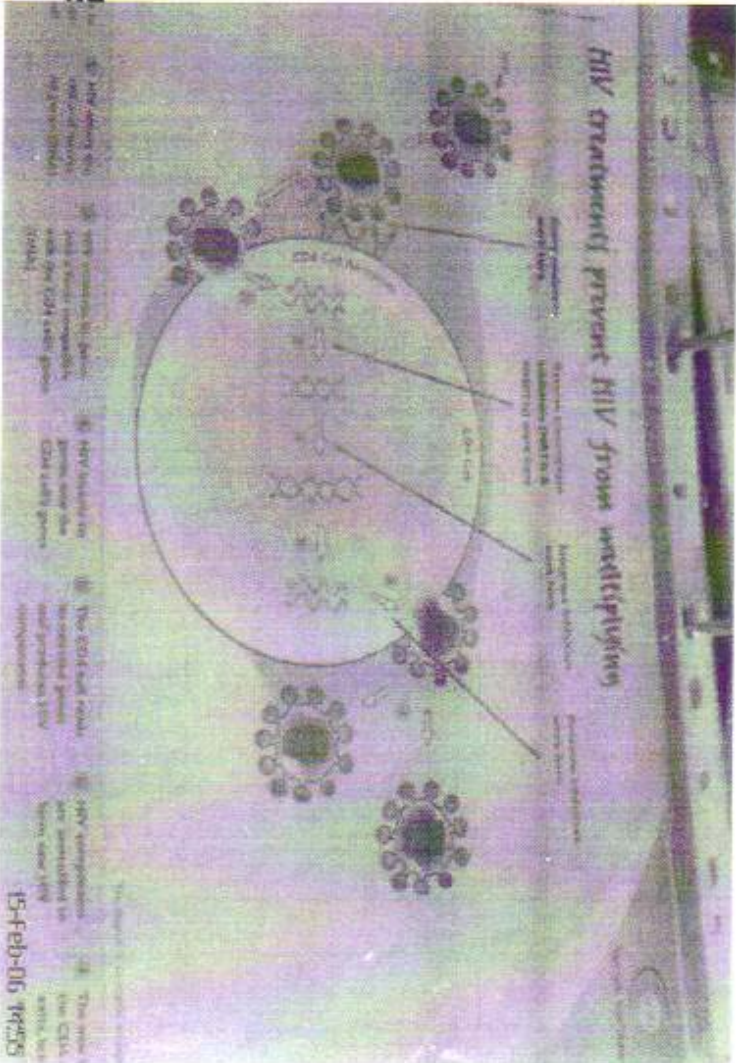
**TEAM
PRESENTS**

**DRUG LITERACY TRAINING
FOR NEW CLIENTS**

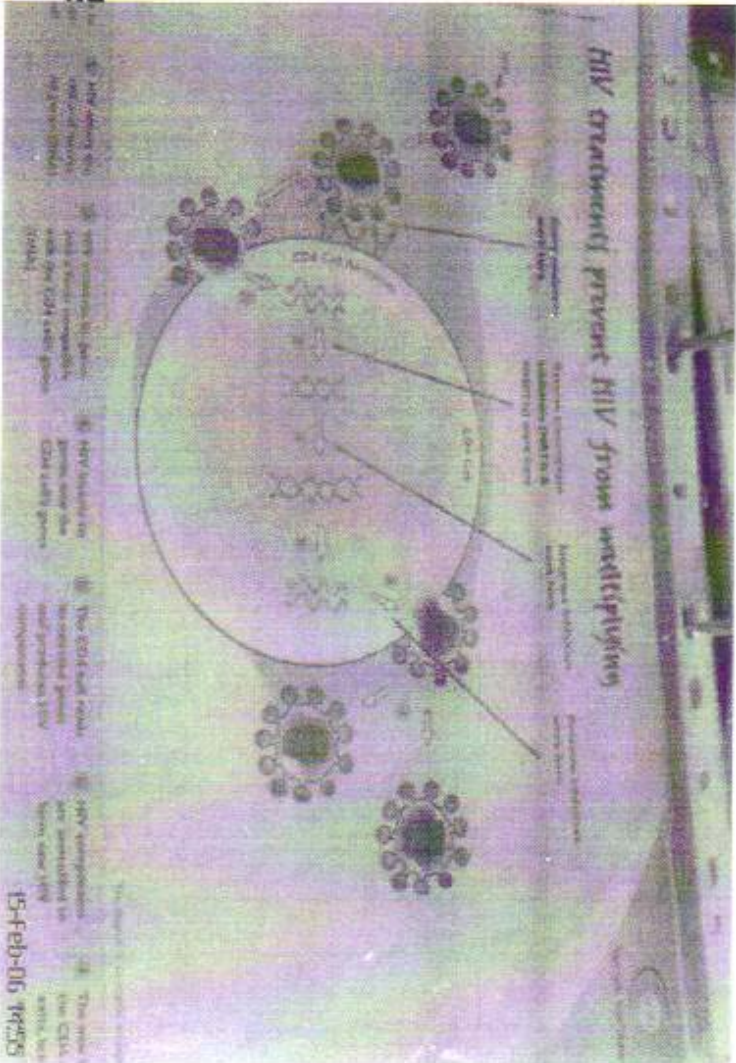
Compiled by K Sankar 2005



HIV TREATMENT PREVENT HIV FROM MULTIPLYING



HIV TREATMENT PREVENT HIV FROM MULTIPLYING



INTRODUCTION

The Pharmacy ARV Team Comprises:

1. The Drug Literacy Counsellor

Counsels you on the drugs you will be taking, side effects you can expect, precautions and safe keeping/storage of your medicines

2. The Pharmacist

Checks for allergies, drug interactions, etc before drugs are issued to you

Data Capturer

Captures all necessary information including your medication details



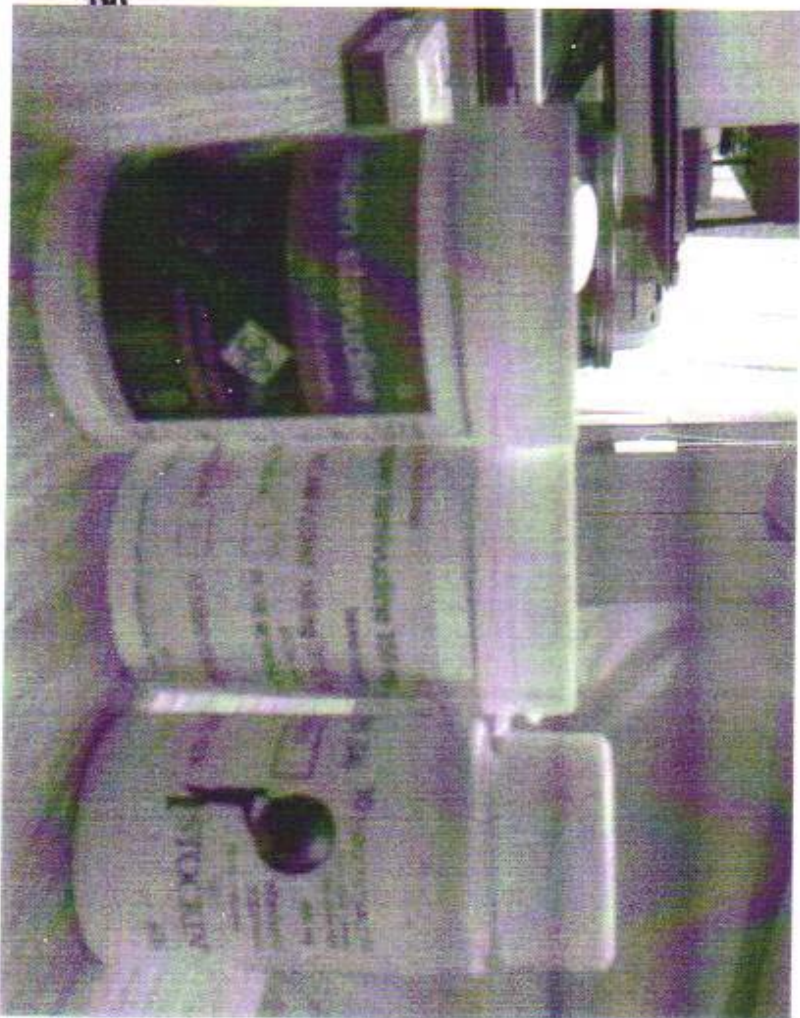
DRUG LITERACY

You will be taking 3 ARV drugs either from
Regimen 1a or 1b

- Regimen 1a
 - Stavudine 30 mg and 40 mg (d4T)
 - Lamivudine 150 mg (3TC)
 - Efavirenz 600 mg (Stocrin)
- Regimen 1b
 - Stavudine 30 mg and 40 mg (d4T)
 - Lamivudine 150 mg (3TC)
 - Nevirapine 200 mg (NVP)



ARV DRUGS REGIMEN 1a



8

ARV DRUGS REGIMEN 1b



DRUG LITERACY

- You must take your medicines everyday at the correct time **12 hourly** except **Efavirenz (Stocrin)** which you will take at **night only**
- If you are on Nevirapine, you will take it **once daily** (morning dose), for the **1st 2 weeks**. **After 2 weeks** you will take it **twice daily** (morning and night)



DRUG LITERACY continued...

Why is it so important to always take the pills correctly?

- A certain level of drugs in the blood is necessary to stop the virus from multiplying.
- If the drugs are not taken at regular intervals, this level will drop and some stronger viruses will continue to multiply.
- If this happens several times, the virus may become resistant. This means the ~~strong~~ will no longer be effective and different drugs will need to be used.



DRUG LITERACY continued...
Special precautions with Stocrin and
Nevirapine

- If you are on Stocrin, it is your responsibility to take Depo-provera Injection every three months to prevent pregnancy
- If you intend becoming pregnant, do not choose the Stocrin regimen as Stocrin causes birth defects
- Please advise your health care worker if you are on TB treatment. Nevirapine is best avoided with TB medicines, as it is also harsh to the liver



DRUG LITERACY continued...

- You will need to take Co-trimoxazole (Bactrim) once daily, everyday, unless stopped by the doctor

- **DO NOT TAKE HERBAL MEDICINES** (Cell Food, Moducare, Spirulina, Oxycell) once you start ARVs. Vitamin supplements issued at your hospital or clinics are fine



DRUG LITERACY continued...

What happens when I forget a dose?

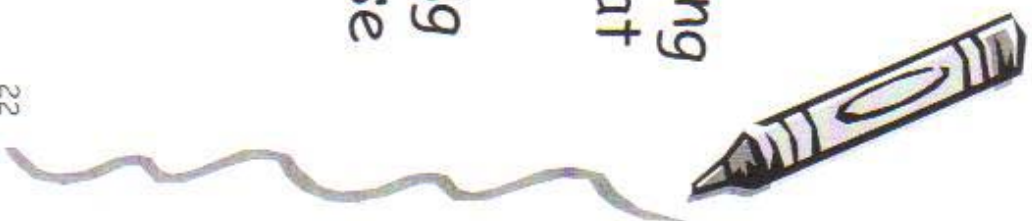
- If you remember the missed dose within 1 hour of the correct time, take it straight away.
- If it is longer than 1 hour, skip that dose completely.
- **DO NOT TAKE A DOUBLE DOSE**
- Remember, it is important to take **your medicines on time everyday**



DRUG LITERACY continued...

What happens when I vomit a dose?

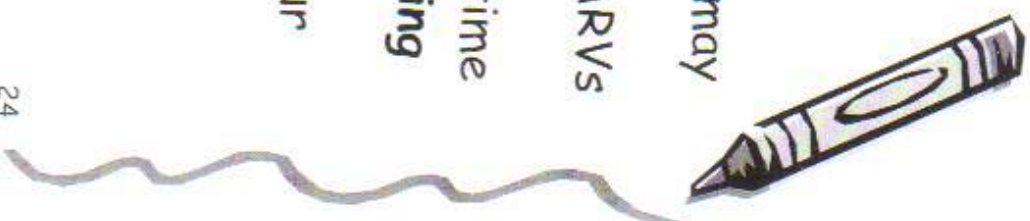
- If you vomit within an hour of taking your medicines, remember to repeat the dose
- If you vomit after an hour of taking your tablets, do not repeat the dose
- Do not stop taking your medicines unless your doctor advises you to



DRUG LITERACY continued...

What about side effects?

- The ARV drugs have many side effects which may or may not affect you. Do not be disturbed.
- Some side effects occur soon after starting ARVs and disappear after a few weeks
- Others may develop later and get worse with time
- **Do not stop taking your ARVs without speaking to the doctor.**
- If the side effects are severe, please visit your nearest clinic or hospital



DRUG LITERACY continued...

What sort of side effects might I get?

- Different drugs have different side effects. The most common early side effect is nausea and feeling tired
- Other side effects include rashes, tingling or burning sensations in the hand or feet, loss of appetite and abdominal pain



~~Side~~ effects may be mild, moderate or severe



DRUG LITERACY continued...

What you need to tell your Health Care Worker at every every visit

- Report any allergies you have had before commencing ARV drugs eg. Rash with Bactrim or Aspirin
- Report any illnesses you suffer from before and after ARV medicines eg. Headaches, fever, cramps, tiredness, pain, numbness/burning in feet and hands, stomach and liver problems, high cholesterol
- Advise your doctor or pharmacist if you were previously on ARVs or exposed to Nevirapine eg. If you were on the PMTCT programme



DRUG LITERACY continued...

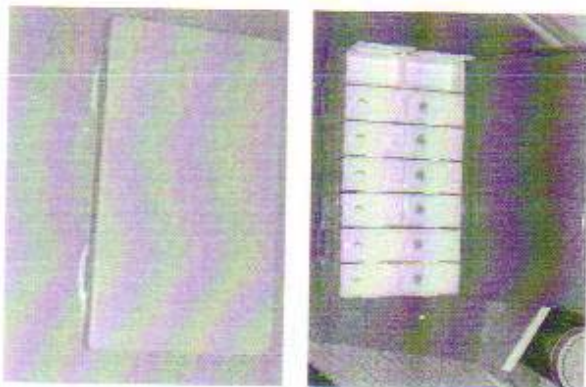
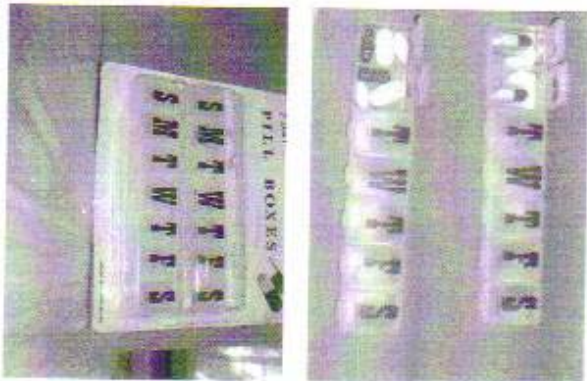
How can you master adherence to your

ARVs

- Choose a time that fits in with your daily routine eg. Brushing your teeth, watching TV.
- Learn the names of your medicines
- Remember to take your medicines everyday on time. At all costs avoid missing doses. **DO NOT DOUBLE YOUR DOSES TO CATCH UP**



Pill Boxes



DRUG LITERACY continued...

How can you master adherence to your ARVs continued...

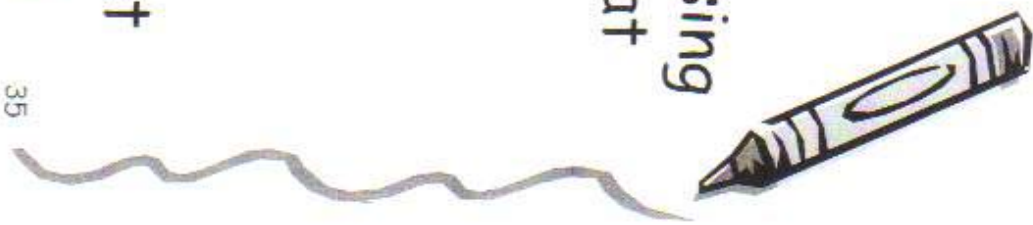
- Use the adherence calendar given to you, your diary, alarm clock, cell phone reminder, pill box or get your treatment supporter to miss call or SMS you
- If you expect not to be home or are busy travelling somewhere at your medication time, please carry some medicines together with some water or juice so that ~~you~~ you can take your medicines on time and not miss a dose



DRUG LITERACY continued...

How can you master adherence to your ARVs continued....

- If you vomit within an hour of missing your medicines, remember to repeat the dose
- Do not stop taking the medicines unless your doctor advises you to
- If you experience severe side effects, do not stop taking your ~~medicines~~ medicines. Rather visit your nearest clinic or doctor who will advise you



DRUG LITERACY continued...

How can you master adherence to your ARVs continued....

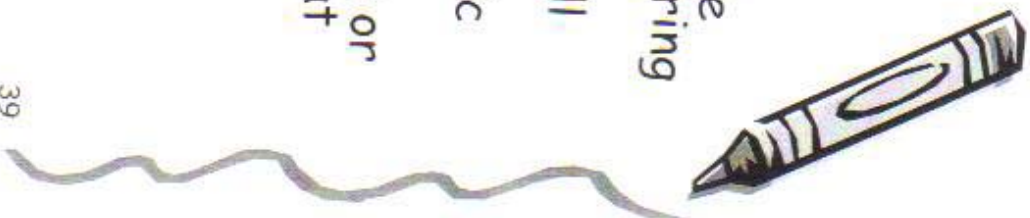
- Never go without tablets. If you do happen to run out of medicines, do not hesitate to contact your clinic, hospital or pharmacy
- Remember to plan financially for your next visit to your hospital/clinic ie. Your taxi or busfare, your fees, ~~something~~ something to eat, etc.



DRUG LITERACY continued...

Your appointments

- Remember to keep all your appointments at the hospital or clinic even if you have medicines. Bring your unused medicines at every visit.
- **Never go without tablets.** If you think you will run out of medicines before your next appointment, please call at the hospital or clinic where you collect your medicines.
- If you have to attend a clinic, hospital, dentist or pharmacy, please inform the health worker that you are on ARVs. It is advisable to carry your medicines with.



DRUG LITERACY continued...

How to care for your medicines

- Store in a cool, dry place, away from heat and light
- Keep away from children
- Wash your hands before handling your medicines
- Do not pour your medicines onto the palm of your hand. Rather use the lid of the container.
- Do not share your medicines with anyone ~~even~~ if they are on the same medicines



DRUG LITERACY continued...

General

- Practice safe sex. **ALWAYS USE A CONDOM** to prevent passage of resistant strains of virus
- You are not alone. Join a Support Group in your area and make life more meaningful
- Be positive and share your success with your friends and relatives. Encourage them to attend VCT clinic and also enjoy the benefits of being on treatment
- Eat healthy foods and exercise daily
- **AVOID ALCOHOL**
- HIV can be transmitted to the baby in utero, at delivery and by **BREASTFEEDING**. If you intend to become pregnant, it will be in your interest to consider your CD4 levels, your viral load and your clinical status. Consult your health care worker for more advice



ARV TABLETS



45

ISSUE OF MEDICINES

CONGRATULATIONS!!!!

- You are now ready to receive your 1st 2 weeks of medicines
- Your medicines are packed in packets with the morning and evening doses separated
- If you on Regimen 1a you will take d4t and 3TC in the morning and d4t, 3TC and Stocrin at night
- If you are on Regimen 1b you will take d4t, 3TC and Nevirapine in the morning and d4t and 3TC at night for the 1st 2 weeks. After 2 weeks you will take d4t, 3TC and Nevirapine in the morning and at night.



Medicine Issues

- VISIT 1
 - 2 weeks supply issued on boards
- VISIT 2
 - 2 weeks supply issued on boards
 - Patients on NVP take NVP twice daily
 - Liver function tests for patients on NVP
- VISIT 3
 - 1 month supply of medicine issued
 - Patients learn how to open containers
 - Patients learn how to use the calendar as an adherence tool
 - Liver function tests for patients on NVP
- VISIT 4
 - 1 month supply - enforce adherence
 - Liver function tests for patients on NVP
- MONTHLY VISITS THEREAFTER





The End

Questions???

