

**THE SOCIO-ECONOMIC ASPECTS INVOLVED IN COMPLIANCE TO
ANTIRETROVIRAL THERAPY: PRINCESS MARINA HOSPITAL,
GABORONE**

BY

MPHO KELETSO PODISI

Submitted in partial fulfilment of the requirement for the degree

MASTER OF SOCIAL SCIENCE

In

SOCIAL HEALTH CARE

At the

UNIVERSITY OF PRETORIA

Supervisor: Dr J. Sekudu

May 2005

ACKNOWLEDGEMENTS

My appreciation and gratitude are extended to the following:

- ❖ Princess Marina Hospital, for granting permission for the research to be conducted
- ❖ The patients who participated in this study
- ❖ Dr J. Sekudu, my supervisor, for her incredible guidance and invaluable support
- ❖ My husband Baiti, and daughter Tlotlo for their encouragement and love
- ❖ Princess Marina IDCC personnel for their cooperation and support when conducting interviews
- ❖ Ministry of Health for the scholarship
- ❖ God Almighty for the guidance and strength and for making it all possible.

SUMMARY

TITLE: THE SOCIO-ECONOMIC ASPECTS INVOLVED IN COMPLIANCE TO ANTIRETROVIRAL THERAPY

CANDIDATE: Mpho Keletso Podisi
DEPARTMENT: Social Work-University of Pretoria
SUPERVISOR: DR J. Sekudu
DEGREE: MSD (SW) Health Care

This study emanates from the need to understand the socio-economic factors that might have contributed to the patients dropping out of the MASA antiretroviral therapy programme in Botswana. The aim of the study was to explore the socio-economic factors that are involved in compliance to antiretroviral therapy. It is crucial to know what these factors are and the strategies that can be deployed to address them. This will assist in the achievement of the programme goals.

The type of research that was used is applied research. One of the primary rationales of applied research is that the study may have some practical use. The purpose of applied research is to contribute knowledge that will help people understand the nature of the problem in order to intervene, and this was the main motivation for this study. Since the MASA programme was launched, there were some patients who were 'lost to follow-up'. As a result, there was a need to understand the reasons behind this phenomenon, so that the patients who are enrolled on the programme are retained.

In order to gain an in-depth understanding of how the socio-economic factors affect compliance with antiretroviral therapy, phenomenology was used as a research strategy. Using the phenomenological strategy helps in

understanding the nature or meaning of the respondents' everyday experiences and to transform experiences into consciousness.

The sampling method that was used is probability sampling, utilising availability sampling. The population for this study was HIV positive adults who had dropped out of the MASA Programme at Princess Marina Hospital, IDCC clinic in Botswana. The data collection instrument that was used was the interview schedule.

From the conclusions, it is apparent that the socio-economic factors are crucial and should therefore be given more attention if better compliance is to be realised. In the same breath, patients require counselling that will focus, not only on the medical aspects of HIV/AIDS but also on the socio-economic factors. As shown in this study it is predominantly the socio-economic factors that led to patients dropping out of the programme. Social workers can play a critical role in this regard as they are equipped with counselling skills.

Lastly, the conclusions and recommendation arising from this study are provided.

KEY CONCEPTS

English	Afrikaans
❖ Families	Gesinne
❖ Economic	Ekonomies
❖ Counselling	Berading
❖ Compliance	Inskiklikheid
❖ Social support	Maatskaplikeondersteuning
❖ Social worker	Maatskaplikewerker
❖ Socio-economic	Sosiaal-ekonomies
❖ Health personnel	Gesondheidbeampte
❖ HIV positive patient	MIV positief pasiënt
❖ Antiretroviral therapy	Antiretroviraletherapie

ABBREVIATIONS

❖ HIV	Human Immunodeficiency Virus
❖ HTLV	Human T-cell Lymphotropic Virus
❖ AIDS	Acquired Immunodeficiency Syndrome
❖ ARV	Antiretroviral Therapy
❖ UNAIDS	The Joint United Nations Programme on AIDS
❖ PLHAs	Persons Living with HIV/AIDS
❖ HAART	Highly Active Antiretroviral Therapy
❖ ACHAP	African Comprehensive HIV/AIDS Programme
❖ SIV	Simian Immunodeficiency Virus
❖ STI	Sexually Transmitted Infection
❖ WHO	World Health Organisation
❖ GPA	Global Programme on AIDS
❖ PMTCT	Prevention of Mother to Child Transmission
❖ IDCC	Infectious Disease Control Clinic
❖ HBC	Home Based Care
❖ IEC	Information Education Communication

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	2
SUMMARY	3
KEY CONCEPTS	5
ABBREVIATIONS.....	6
TABLE OF CONTENTS	7
CHAPTER 1	11
GENERAL ORIENTATION	11
1.1 INTRODUCTION.....	11
1.2 THEORETICAL BACKGROUND.....	12
1.2.1 HIV/AIDS impact in Botswana	14
1.3 PROBLEM FORMULATION.....	19
1.4 PURPOSE, GOAL AND OBJECTIVES OF THE STUDY	20
1.4.1 Purpose of the study	20
1.4.2 Goal of the study	21
1.4.3 Objectives of the study	21
1.5 RESEARCH QUESTION.....	21
1.6 RESEARCH APPROACH	22
1.7 TYPE OF RESEARCH.....	23
1.8 RESEARCH DESIGN AND METHODOLOGY	24
1.9 PILOT STUDY	26
1.10 RESEARCH POPULATION AND THE SAMPLING METHODS	27
1.11 ETHICAL ASPECTS	28
1.11.1 Informed consent.....	28
1.11.2 Voluntary participation.....	29
1.11.3 Deception of subjects.....	29
1.11.4 Confidentiality	30
1.11.5 Action and competence of researcher	30
1.11.6 Harm to respondents.....	30
1.11.7 Debriefing of respondents	31
1.11.8 Publication of findings	31

1.12	DEFINITION OF KEY CONCEPTS	32
1.12.1	AIDS: Acquired Immunodeficiency Syndrome	32
1.12.2	ARV: Antiretroviral Drug	32
1.12.3	Compliance	32
1.12.4	HIV: Human Immunodeficiency Virus	33
1.12.5	Socio-Economic	33
1.13	CONTENTS OF THE RESEARCH REPORT	34
1.14	PROBLEMS AND LIMITATIONS OF THE STUDY	34
CHAPTER 2	35
THE PHENOMENON OF COMPLIANCE TO ANTIRETROVIRAL THERAPY, HIV/AIDS AND THE SOCIO-ECONOMIC ASPECTS INVOLVED.....	35
2.1	INTRODUCTION.....	35
2.2	THE BIOLOGY OF HIV/AIDS	36
2.2.1	Primary infection	38
2.2.2	Early HIV infection.....	39
2.2.3	Intermediate HIV infection	40
2.2.4	Acquired immunodeficiency syndrome	41
2.3	HIV TYPES AND SUBTYPES	42
2.3.1	HIV-1 Sub-type distribution: predominant sub-types.....	42
2.3.2	HIV-2.....	43
2.3.3	CD4 Cell Count	43
2.4	ANTIRETROVIRAL THERAPY	43
2.4.1	Goals of therapy	44
2.4.2	Indications for therapy	45
2.4.3	Appropriate time to start antiretroviral therapy, WHO Guidelines (March 2004).....	46
2.4.4	CD4 count	46
2.4.5	Clinical stages	46
2.4.6	Appropriate time to start antiretroviral therapy: Botswana guidelines....	47
2.5	BOTSWANA: THE MASA ARV PROGRAMME.....	48
2.5.1	Challenges and lessons for MASA Programme.....	52
2.6	ADHERENCE AND RESISTANCE.....	53
2.7	PSYCHO-SOCIAL ASPECTS	62
2.7.1	Responses to a person living with AIDS.....	65
2.7.2	Social barriers.....	66

2.7.3	HIV prevention and supportive care	67
2.7.4	Confidentiality and Disclosure	68
2.8	ECONOMIC ASPECTS.....	69
2.9	POLITICAL COMMITMENT	73
2.10	LITERACY AND POVERTY	75
2.11	CONCLUSION	78
CHAPTER 3	80
THE EMPIRICAL FINDINGS OF THE SOCIO-ECONOMIC ASPECTS INVOLVED IN COMPLIANCE TO ANTIRETROVIRAL THERAPY	80
3.1	INTRODUCTION.....	80
3.2	RESEARCH METHODOLOGY	80
3.3	RESEARCH FINDINGS	81
3.3.1	Central themes.....	81
3.3.1.1	The time respondents got to know their HIV status.....	81
3.3.1.2	Reasons for testing.....	83
3.3.1.3	Respondents' feelings when they were diagnosed	86
3.3.1.4	Respondents' feelings when they started ARVs.....	89
3.3.1.5	Ways in which ARVs improved respondents' quality of life	94
3.3.1.6	Reasons why respondents stopped going to the hospital for follow- up assessment and treatment.....	98
3.3.1.7	Reasons that led to respondents not taking treatment as prescribed.....	105
3.3.1.8	Ways in which respondents' quality of life changed since stopping ARVs.....	111
3.3.1.9	Respondents' feelings when they stopped ARVs.....	112
3.3.1.10	Ways in which respondents feel they could have been assisted financially to enhance compliance.....	115
3.3.1.11	Ways in which respondents feel family could have been supportive to assist them with compliance.....	117
3.3.1.12	Respondents' feelings about service from IDCC staff	121
3.3.1.13	Respondents' feelings on what could have been done to assist them with compliance.....	124
3.3.1.14	Things that respondents would need in place if they were to resume ARV treatment.....	127
3.4	SUMMARY	129

CHAPTER 4	133
SUMMARY, CONCLUSIONS AND RECOMMENDATIONS	133
4.1 INTRODUCTION.....	133
4.2 CHAPTER 1	133
4.2.1 SUMMARY: GENERAL ORIENTATION.....	133
4.3 CHAPTER 2.....	135
4.3.1 LITERATURE STUDY	135
4.3.1.1 The biology of HIV/AIDS.....	135
4.3.1.2 HIV types and sub-types.....	135
4.3.1.3 Antiretroviral Therapy	135
4.3.1.4 Botswana MASA ARV Programme	135
4.3.1.5 Adherence and resistance	136
4.3.1.6 The socio-economic aspects	136
4.3.1.7 HIV prevention and social support	136
4.3.1.8 Intervention.....	136
4.4 CHAPTER 3.....	137
4.4.1 RESEARCH FINDINGS	137
4.4.1.1 The time respondents got to know about their HIV status	137
4.4.1.2 Reasons for testing.....	137
4.4.1.3 Respondents' feelings when diagnosed HIV positive	137
4.4.1.4 Respondents' feelings when they were started with ARVs.....	137
4.4.1.5 Ways in which ARVs improved the respondents' quality of life ...	137
4.4.1.6 Reasons why respondent stopped going for follow-up treatment	138
4.4.1.7 Reasons that led to respondents not taking treatment	138
4.4.1.8 Ways in which respondents' quality of life changed since stopping ARVs.....	138
4.4.1.9 Respondents' feelings when they stopped ARVs.....	138
4.4.1.10 Respondents feelings on how they could have been assisted financially.....	138
4.4.1.11 Respondents' feelings on how family could have been supportive.....	139
4.4.1.12 Respondents' feelings about service from IDCC personnel	139
4.4.1.13 Respondents' feelings on what could have been done to assist them with compliance.	139
4.4.1.14 Things respondents would need in place if they were to resume ARV treatment.....	139

4.5	CONCLUSIONS.....	139
4.6	RECOMMENDATIONS.....	142
4.6.1	RECOMMENDATIONS FROM THE EMPIRICAL STUDY.....	142
4.6.2	RECOMMENDATIONS FOR THE SOCIAL WORK PROFESSION....	144
4.6.3	RECOMMENDATION FOR FURTHER RESEARCH.....	144
	BIBLIOGRAPHY	146

CHAPTER 1

GENERAL ORIENTATION

1.1 INTRODUCTION

HIV/AIDS is a disease that is ravaging millions of people in the world today. According to the researcher's observation, the disease has deprived families of their loved ones, has rendered families poor, and is causing a lot of anxiety, fear, despair and hopelessness. To date, HIV/AIDS has no cure and is continuing to spread unabated. The economically productive workforce is dying, plunging countries into an abject state in their economies.

UNAIDS (2003:1) states that in 2002, more than three million people worldwide died of HIV/AIDS. The report estimates that 42 million people worldwide are already living with the virus- three quarters of the total death toll of world war two.

On the next eight years, UNAIDS (2003:1) estimates that a further 45 million people will become infected with HIV in 126 low and middle-income countries "unless the world succeeds in mounting a drastically expanded, global prevention effort."

One of the attempts to fight the HIV/AIDS pandemic is through treatment with antiretroviral drugs, which are costly and as a result out of reach for many developing countries.

The Southern African Journal of HIV Medicine (2002:102) states the following as the primary goals of ARVs:

- ❖ Maximal and durable suppression of viral load
- ❖ Restoration and/ or preservation of immunological function
- ❖ Improvement of quality of life

❖ Reduction of HIV-related morbidity and mortality

According to Libman & Witzburg (1996:486), ARV is the specific therapy to control viral replication in the management of HIV infected patients.

The ARV programme in Botswana was started in 2002 as a response to the HIV/AIDS pandemic which is ravaging the country. The response has been good so far, and more than 9000 patients have enrolled in the programme at Princess Marina Hospital.

However, the programme has been confronted by some challenges, which have affected compliance to ARVs. These include issues of nutrition, treatment side-effects, financial problems, lack of social support, stigma and discrimination, staff shortage, pill burden and complexity of the regimen, congestion at the clinic and transportation problems. These issues were established during the researcher's discussions with the patients. This called for scientific investigation into these issues so that the implementation of the ARV Programme could be tailored to meet the needs of the patients.

1.2 THEORETICAL BACKGROUND

Botswana's population is 1,680,863, compared with 1,326,796 in 1991. The population growth rate has been declining over the years and the HIV/AIDS pandemic has contributed to the population decline in recent years. Also, factors such as declining fertility rates, increased women participation in economic activities, increased literacy rates, access to better health care, may have a profound effect on population growth (Botswana Population and Housing Census, 2001).

Botswana's population density has increased from two persons in 1991 to three persons per square kilometre in 2001 (National Development Plan 9, 2003/2004:18).

National Development Plan 9 (2003/2004:24) further states that poverty remains one of the major development challenges for Botswana. In 1994, it was estimated that 47% of households in Botswana were living below poverty datum line. The data also indicated that 23% of the population lived on less than US\$1 per day. Rural areas were the most affected. The percentage of the population living below the poverty datum line is estimated to have fallen to 36.7% by 2001. The goal of Vision 2016 is, however, to reduce the proportion of the population living below appropriate poverty datum line to 23% by the year 2007 and to zero by the year 2016.

According to National Development Plan 9 (2003/2004:25), the 2000 study on the Macro-Economic Impacts of HIV/AIDS in Botswana points out that, in the long term, with the current prevalence rates, the proportion of households below the poverty datum line will rise by 6%, while that of poor individuals will rise by 4%. It predicts that the national income dependency ratio will rise from 5.4 to 6.4, that is, “every income earner can expect one extra dependent as a result of HIV/AIDS over the next ten years.” Unless the government continues with HIV/AIDS social programmes, the situation is expected to be worse for the poorest 25% of the households, where “every income earner in this category can on average expect an extra eight dependents as a result of HIV/AIDS”.

Since the first HIV case in Botswana was reported in December 1985, the epidemic has progressed rapidly throughout the country, affecting all strata in society. By 2001, the estimated HIV prevalence reached 35.4% among pregnant women attending antenatal clinics (Botswana Sentinel Surveillance 2002:9).

According to HIV/AIDS Policy (1998:2), several factors are thought to have contributed to the rapid spread of HIV in Botswana. Among them are the extreme mobility of the population combined with good communication system, and the high rate of sexually transmitted infections (henceforth to be referred to as STIs), the presence of which causes a manifold increase in an

individual's chance of being infected during sexual contact with an HIV seropositive partner. In addition, sexual behaviour patterns, which include having multiple partners and frequent change of partners, are accepted as the norm, and common in both urban and rural communities. Rapid urbanisation (approximately 45% of the population now live in urban areas) has led to the breakdown of traditional mechanisms for controlling social and sexual behaviour. Poverty and relative lack of power among women are also of significance.

The researcher notes that, if the current risky sexual behaviour and attitudes about HIV/AIDS do not change, Botswana is likely to face an explosion of HIV infections, which will have a negative impact on the economy at the micro and macro level.

1.2.1 HIV/AIDS impact in Botswana

Government of Botswana Country Report on HIV/AIDS (2002:11-12) states the following:

- ❖ 21.0% young people aged 15 -19 years are HIV infected
- ❖ 37.4% young people aged between 20 -24 are HIV infected
- ❖ 21% to 40% of infants born from HIV infected mothers are likely to be infected
- ❖ 2.4% syphilis prevalence
- ❖ 15% of national donated blood are discarded, 9% due to HIV and 6% due to other diseases.
- ❖ Median age at first sex is 19 years for males and 17 years for females.
- ❖ More than one in three Batswana between 15-49 years are HIV positive
- ❖ An estimated 320,000 Batswana are living with HIV (0 -64+years)
- ❖ An estimated cumulative 138,000 Batswana have died of AIDS by 2002; an additional 263,000 are likely to die by 2010 in the absence of ARV treatment.

The above-mentioned report further states that HIV prevalence in the country appears to have stabilised over the last five years as revealed by the annual sentinel surveillance. The pattern is further supported by data generated from the voluntary counselling and testing centres as well as Prevention of Mother to Child Transmission (PMTCT) Programme data. From reported surveys, specific behaviours support the plateau of the epidemic. These include high condom use, reduced number of sexual partners and high awareness levels.

Furthermore, through its MASA Programme, (a Setswana word meaning 'new dawn') which is the Anti Retroviral Therapy (ARV) Programme, the government of Botswana has taken a bold step to provide ARV therapy free of charge to all Batswana who need it. The therapy promises renewed hope for Batswana to live longer, and healthier lives.

Of the estimated 260,000 HIV positive adults in Botswana, about 110,000 are estimated to require ARV therapy. The plan, based on the supply-demand model, proposed a phased approach to treatment commencing with four priority groups. To date, the MASA programme has enrolled over 9000 patients, of whom more than 6000 are on treatment (Management and Development Publication 2003:11).

According to Botswana Guidelines on Antiretroviral Therapy (2002:13-14), each time a patient fails a treatment regimen, the question of adherence to the drug regimen must be raised and carefully enquired into. Poor compliance is a common reason for treatment failure. This emphasises the need for adherence counselling and monitoring at all stages of HIV treatment. If poor adherence is considered the underlying cause for treatment failure, the treatment should be stopped until the reasons for poor adherence have been addressed.

The relationship between the clinician and the patient must accommodate the need for ongoing education, respect, and support required in such demanding

regimens. The treating doctor should restrain his enthusiasm to commence therapy and allay the patient's anxiety regarding its commencement until both are prepared to meet the adherence needs of the subsequent regimens. In addition, follow-up consultations with family and caregivers if possible, can assist in this process (Andrews, 2002:45).

Andrews (2002:45) gives the following reasons for regimen failure:

- ❖ Counselling and education
- ❖ Side-effects
- ❖ Social and family issues
- ❖ Financial
- ❖ Regimen planning

In addition, the researcher notes the following medical and social factors as factors associated with decreased adherence to ARVs:

- ❖ Food restrictions
- ❖ Depression
- ❖ Relationship problems
- ❖ Confidentiality and disclosure issues
- ❖ Frequency of dosing
- ❖ Pill burden and complexity of regimen
- ❖ Patient preparedness
- ❖ Lack of social support
- ❖ Alcohol and other mood altering drugs
- ❖ Social isolation
- ❖ Negative health beliefs
- ❖ Lack of privacy
- ❖ Fear of stigma and rejection
- ❖ Low literacy levels
- ❖ Financial aspects
- ❖ Transportation

The researcher further notes that the degree to which a regimen fits into the patient's daily schedule greatly influences adherence. Improving adherence is an ongoing exercise, founded in the empowerment of the patient and the expertise of the clinician.

Provision of free ARV therapy to the public is a laudable step that the government of Botswana has taken. Certain factors however, pose challenges for the success and smooth running of the programme.

According to Management and Development Publication (2003:10), insufficient capacity and socio-cultural barriers emerged early as the main challenges to implementing a national ARV programme in Botswana's public health system. Almost a year and a half into the programme, Botswana's ARV programme is rightfully interrogated as to the nature and severity of these capacity constraints. Unfortunately, this may give the impression that all the constraints are specific to ARV therapy. The reality is that HIV/AIDS simply exacerbates the pre-existing structural and systematic deficits, while creating new ones as the incidence continues.

Although there is an emerging consensus that intensive ARV therapies are preferable, it is clear that broad, sweeping guidelines are not appropriate and that ARV treatment should be individualised (Lachman, 2000:107).

Furthermore, once treatment with an effective drug regimen has been started, the most important determinant of success is adherence to the regimen. Therefore, adherence should be addressed and discussed throughout the counselling continuum before the patient starts ARVs and at every follow up visit after commencement of treatment (Botswana Guidelines on Antiretroviral Therapy, 2002:6).

In addition, the above-mentioned document states that the extent to which the goals of therapy are not accomplished indicates the degree of treatment failure.

According to the researcher, this study is important because it will assist implementers and managers of the programme to know which socio-economic aspects are crucial in order to achieve the programme goals and objectives with regard to improving compliance. Based on the findings, measures should be put in place with regard to improving compliance.

In addition, the researcher states that compliance may be estimated by carefully questioning the patient and family members, evaluating the degree of clinical response to therapy, the presence or absence of side effects from drugs, measuring drug serum levels or testing the excretion of the drug in the urine, and counting remaining pills.

Furthermore, the researcher notes that this study will add value to the social work profession because social workers will be in a position to advise from an informed perspective towards the betterment of service delivery. It will also provide the practical knowledge that social workers need to solve the problems they confront at the workplace and will give them the information they need in order to alleviate human suffering and promote social well being.

The researcher is further of the opinion that this study will help bridge current gaps and could be helpful in policy formulation. The researcher is involved in HIV/AIDS work at her work place, therefore the study will be of benefit to her, Princess Marina Hospital as well as Botswana government. The researcher was part of the team that was involved in the initial stage of the programme roll-out in 2002.

The government of Botswana introduced the national ARV policy in 2002 and the researcher is interested to find out which socio-economic factors have had an impact on compliance to the treatment regimen.

1.3 PROBLEM FORMULATION

Fouche (2002:106) states that three factors determine the manner in which research problems are formulated; the unit of analysis, the type of research question and the research approach.

During problem formulation the researcher is able to decide on the group or individuals the researcher will collect data.

The Management and Development Publication (2003:10) points to the challenges associated with launching Botswana's National ARV Programme, and states that insufficient capacity and socio-cultural barriers emerged early as the main challenges to implementing a national ARV programme in Botswana's public health sector system. Almost a year and a half into the programme, the programme is rightfully interrogated as to the nature and severity of these capacity constraints.

The researcher points out that because of the challenges facing the programme, some patients who were enrolled in the ARV programme have discontinued the treatment. This therefore raises the issue of compliance with ARVs. If compliance with ARVs is as important as the MASA programme purports it to be, then proper guidelines to retain patients in the programme is essential as well as having practical follow up strategies in place.

If the MASA programme is to achieve its goals, the programme should give the issue of monitoring and follow-up of patients careful consideration. To enhance its effectiveness, the programme needs to recruit personnel who will focus on follow-ups in order to achieve the goals of which the ultimate is to reduce the impact of HIV/AIDS.

According to the researcher's observation, patients enrolled in the ARV programme experience specific problems such as mentioned below:

- ❖ Long distance travel to the hospital for treatment
- ❖ Some patients are too weak and too sick to travel
- ❖ Financial problems to be able to pay for transportation and food
- ❖ Severe side effects from ARVs
- ❖ Stigma problems; what will people say when they see me taking ARVs?
- ❖ Lack of social support
- ❖ Insufficient infrastructure/overcrowding
- ❖ Inadequate personnel

In summary, the problem statement for this study is as follows: The MASA Programme has experienced a positive response with regard to patients enrolling for ARV treatment. There is however a problem of retaining all the patients in the programme. The reason for this occurrence needs to be investigated. The problem formulation for this study is the socio-economic factors that are involved in compliance with ARVs.

1.4 PURPOSE, GOAL AND OBJECTIVES OF THE STUDY

1.4.1 Purpose of the study

The purpose of this study is exploratory. According to Bless and Higson-Smith (1995:42), the purpose of exploratory research is to gain insight into a situation, phenomenon, community, or person. The need for such a study could arise out of a lack of basic information on a new area of interest.

Babbie (2004:87) points out that exploratory research is conducted to explore a topic, that is, to start to familiarise a researcher with that topic. This approach typically occurs when a researcher examines a new interest or when the subject of study itself is relatively new.

The Botswana ARV Programme was started in 2002 and the programme being relatively new, the researcher wants to explore the issues that are involved in compliance with ARVs and thus come up with ways in which these could be addressed.

1.4.2 Goal of the study

Hornby Oxford Advanced Learner's Dictionary (2000:508) defines goal as something you hope to achieve.

The researcher aims to explore the socio-economic aspects that are involved in compliance with ARVs.

1.4.3 Objectives of the study

The objectives of this study are as follows:

- ❖ To provide a theoretical framework regarding HIV/AIDS, ARV treatment and compliance.
- ❖ To explore the socio-economic aspects that are involved in compliance with ARVs.
- ❖ To provide recommendations for improved service delivery to patients on ARVs in order to improve compliance

1.5 RESEARCH QUESTION

According to Lee (1997:40), the research question is an important part of the research project. It is vital that the question is posed in a broad and flexible manner so that the subject is not restricted and therefore has optimal opportunity to express his personal experience freely. The subject must be able to articulate the aspects of the experience that are important to him. The research question should therefore not be prescriptive or rigid with regard to the topic being researched.

Ritchie & Lewis (2003:48) argue that a research question needs to be clear, intelligible and unambiguous, focussed but not too narrow, not too abstract, relevant and useful, informed by and connected to existing research or theory and with the potential to make an original contribution or to fill a gap.

The research question for this study is: **what are the socio-economic aspects that are involved in compliance with ARVs?**

1.6 RESEARCH APPROACH

The researcher notes that there are two types of approaches to research, namely the qualitative and quantitative approaches.

Fouche & Delport (2002:79) allude that the qualitative paradigm stems from an anti-positivistic, interpretative approach, is idiographic, thus holistic in nature, and aims mainly to understand social life and the meaning that people attach to everyday life. It refers to research that elicits participant accounts of meaning, experience or perceptions. It also produces descriptive data in the participant's own written or spoken words. It thus involves identifying the participant's beliefs and values that underlie the phenomena. The qualitative research is therefore concerned with understanding rather than explanation, naturalistic observation rather than controlled measurement, and the subjective exploration of reality from the perspective of an insider as opposed to outsider perspective that is predominant with non-statistical methods and small samples often purposively selected.

O'Sullivan, Rassel, & Berner (2003:38) postulate that qualitative studies describe specific features of each individual, organisation, jurisdiction, or programme. The researcher studies few cases and obtains extensive information on each case and setting. Qualitative studies may involve extensive fieldwork; the researcher goes to where the cases are located and obtains information on them in their natural setting. In this way, the researcher

does not attempt to manipulate any aspect of the situation being studied but takes it as it is.

The researcher used the qualitative research approach in order to gain first hand understanding of the socio-economic aspects involved in compliance with ARV therapy by using interview schedule as a data collection method. Because the respondents used their own language to describe, explain phenomenon, the researcher could understand their situation better. This approach was suitable for this study because it enabled the researcher to gain insight into the actual situation according to how the participants experienced it.

1.7 TYPE OF RESEARCH

The type of research used in this study was applied research. Baker (1994:473) defines applied research as research for which one of the primary rationales is that the study may have some practical use.

According to Patton (2002:217), the purpose of applied research is to contribute knowledge that will help people understand the nature of the problem in order to intervene, thereby allowing human beings to more effectively control their environment.

In applied research, researchers work on human and societal problems and are often guided by findings, understanding and explanations of basic research. They are able to bring their personal insights and experiences into any recommendations that may emerge because they get especially close to the problems under study (Patton, 2002:217).

The researcher used applied research because she wanted the study to have some practical use and contribute towards the improvement of the Botswana ARV Programme.

1.8 RESEARCH DESIGN AND METHODOLOGY

Bless & Higson-Smith (1995:63) allude that a research design can be understood as the planning of any scientific research from the first to the last step. In this sense, it is a programme to guide the researcher in collecting, analysing and interpreting observed facts. It is a specification of the most adequate operations to be performed in order to test a specific hypothesis under given conditions.

Research design addresses the planning of scientific inquiry: designing strategy for finding out something (Babbie & Mouton, 1998:72).

Patton (2002:104) alludes that a research strategy is a tool that can be used in qualitative research. It is more flexible and shows the research goal. It is commonly used in qualitative research. The research strategy that was used for this study is phenomenology.

According to Patton (2002:104), phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences and to transform experience into consciousness. This requires methodologically, carefully, thoroughly capturing and describing how people experience some phenomenon; how they perceive it, describe it, feel about it, judge it, remember it, make sense of it and talk about it with others. To gather such data one must undertake in-depth interviews with people who have directly experienced the phenomenon of interest, that is, they have 'lived experience' as opposed to second hand experience.

The data-collection instrument that was used was an interview schedule. Neuman (1997:231) postulates that an interview schedule is a set of questions read to the respondent by an interviewer, who also records responses. (Compare Neuman, 2000:250.)

According to Greeff (2002:302) an interview schedule is a questionnaire written to guide interviews. This provides the researcher with a set of predetermined questions that might be used as an appropriate instrument to engage the participant and designate the narrative terrain.

Extensive and strategic notes were taken. The researcher states that the purpose for taking notes was explained to the respondents, being that it enables the researcher to capture all that is said and reduces the risk of the researcher inadvertently changing the words of the respondents.

The interview schedule was used because it enabled the researcher to explore the issues in-depth, as relevant questions were asked.

With regard to the interview setting, a conducive, quiet environment was arranged and this was either the participants' homes or Princess Marina Hospital counselling rooms.

Babbie & Mouton (1998:490) allude that data analysis is referred to as all forms of data that was gathered using qualitative techniques, regardless of the paradigm used to govern the research.

According to Patton (2002:437), the researcher has two primary sources to draw from in organising the analysis; first, the questions that were generated during the conceptual and design phase of the study prior to field work, second, analytical insights and interpretations that emerged during data collection.

De Vos (2002:341) states the process of qualitative data analysis and describes the steps as follows:

- a. Collection and data recording
- b. Managing data
- c. Reading, memoing

- d. Describing, classifying, interpreting
- e. Representing, visualising.

The researcher recorded data in a manner that facilitated analysis, for example, finding a conducive environment to take notes. During the reading phase, some editing was done and unnecessary data was eliminated. In describing the data, the researcher took into consideration the respondent's ideas and beliefs and linked them to their settings. This enabled the researcher to bring insights when interpreting the data.

In addition, data was classified into themes in preparation for the final write-up. Data was coded and then analysed. Finally, data was presented in written form.

1.9 PILOT STUDY

According to Barker (2003:327-328), a pilot study is defined as a procedure for testing and validating a questionnaire or other instrument by administering it to a small group of respondents from the intended test population, who will then not be part of the sample. The procedure helps determine whether the test items possess the desired qualities of measurement and the ability to discriminate other problems before the instrument is put into widespread use.

Pilot testing means to try the experimental treatment out on small samples between the actual experiment. If it does not seem to work correctly, it can be modified and re-tested until it is judged ready (Dooley, 1990:218).

The researcher points out that a pilot study can be described as a mini trial study and therefore prepares way for the main study. The pilot study enables the researcher to recognise the loopholes and omissions and they are rectified when preparing for the main study.

The researcher further notes that, this study is not only feasible, but also important to undertake at this stage since the ARV Programme was rolled out in 2002. In addition, the researcher is on a scholarship that covers research, and travel costs.

The researcher conducted the pilot study at the Princess Marina Hospital IDCC clinic in Botswana where the ARV programme is currently running and two respondents were interviewed.

1.10 RESEARCH POPULATION AND THE SAMPLING METHODS

According to Bless & Higson-Smith (2002:437), population is the set of elements that the research focuses upon and to which the results obtained by testing the sample should be generalised.

Babbie (2004:190) alludes that population is the theoretically specified aggregation of study elements.

The population for this study was HIV positive adults who have dropped out of the ARV Programme at Princess Marina Hospital IDCC clinic in Botswana. The researcher made use of Princess Marina Hospital IDCC clinic list of patients who are “lost to follow up”. The researcher was aware that some of these patients might still be alive while others might be dead. The respondents were interviewed in the privacy of their homes and in instances where confidentiality could not be guaranteed in the homes, Princess Marina Hospital counselling rooms were used. The researcher provided transport in instances where interviews had to be conducted at the hospital.

A sample is the subset of the whole population which is actually investigated by a researcher and whose characteristics will be generalised to the entire population (Bless & Higson-Smith, 1995:85-86).

The sampling method that was used was non-probability sampling, utilising availability sampling.

According to Bless & Higson-Smith (1995:88), non-probability sampling refers to the case where the probability of including each element of the population in a sample is unknown, that is, it is not possible to determine the likelihood of inclusion of all representative elements of the population into the sample. Some elements might even have no chance of being included in the sample.

Bless & Higson-Smith (1995:94) state that availability sampling consists of taking all cases on hand until the sample reaches the desired size.

A total of twelve respondents were interviewed. Availability sampling was used because the researcher utilised the Princess Marina Hospital IDCC clinic list of patients who were “lost to follow up” and those patients who were alive and willing, were the ones who participated in the study.

1.11 ETHICAL ASPECTS

According to Barker (2003:147), ethics refers to a system of moral principles and perception about right versus wrong and the resulting philosophy of conduct that is practiced by an individual, group, profession or culture.

1.11.1 Informed consent

Obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, be rendered to potential subjects or their legal representatives (Strydom, 2002:65).

The researcher explained the purpose of this study, the advantages and disadvantages of participating in this study, as well as the risks involved before the respondents could give consent to participate.

1.11.2 Voluntary participation

Social research often, though not always, represents an intrusion into people's lives. The interviewer's knock on the door or the arrival of a questionnaire in the mail signals the beginning of an activity that the respondent has not requested and one that may require a significant portion of his time and energy. Participation in a social experiment disrupts the subject's regular activities (Babbie, 1992:464).

The researcher took careful consideration and ensured that participation in the study was voluntary. Respondents were not coerced to participate in the study and for those who participated, the extent to which they wished to divulge sensitive information was respected. Accurate and complete information was given so that the respondents fully understood the purpose and goal of the investigation. Mentally challenged people did not participate in the study and the researcher communicated in clear, understandable language.

To ensure voluntary participation, the purpose of the study was explained to the respondents, the advantages and disadvantages involved as well as the risks involved in the study.

1.11.3 Deception of subjects

Strydom (2002:66) describes deception of subjects as "deliberately misrepresenting facts in order to make another person believe what is not true, violating the respect to which every person is entitled."

In this regard, the researcher ensured that information given was correct and accurate. The purpose of the study was explained to the respondents and the advantages and disadvantages involved as well as the risks to be expected.

1.11.4 Confidentiality

According to Strydom (2002:67), confidentiality is a continuation of privacy, “which refers to agreements between persons that limit others’ access to private information”.

The researcher ensured that no one would be able to identify the respondents. All information given was treated confidentially. In order to realise confidentiality, only the researcher and the research supervisor had access to data. Interviews were conducted in a place that offered privacy.

1.11.5 Action and competence of researcher

Strydom (2002:69) states that researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation.

The researcher is qualified, competent and skilled to carry out this research and thus able to handle sensitive information very well. In addition, the researcher has done a course in research methodology, has done course work on HIV/AIDS, has done work on ARVs, and is working under guidance of a supervisor.

1.11.6 Harm to respondents

According to Strydom (2002:64), subjects can be harmed in a physical and or emotional manner. Harm to respondents in social science will mainly be of an emotional nature, although physical injury cannot be ruled out completely.

The researcher took measures to protect subjects within reasonable limits by ensuring that the purpose of the study was explained and the potential impact of the study. Debriefing was done after the interview sessions in order to minimise the emotional harm on the subjects. In addition, a conducive and safe environment was arranged for the interviews.

1.11.7 Debriefing of respondents

Debriefing sessions during which subjects get the opportunity, after the study, to work through their experience and its aftermath, are possibly one way in which the researcher can assist subjects and minimise harm. Through debriefing, problems generated by the research experience can be corrected (Strydom, 2002:73).

The researcher provided debriefing sessions immediately after the data collection sessions were completed in order to address the impact of the interview on the respondents.

1.11.8 Publication of findings

The findings of the study must be introduced to the reading public in written form, otherwise even a highly scientific investigation will mean very little and will not be viewed as research (Strydom, 2002:71).

The respondents were informed during interviews that the findings of the study will be published in professional journals. Where necessary and applicable, the respondents will be informed about the findings, as a form of recognition and gratitude for their participation. Princess Marina Hospital will be provided with the information and this has been communicated to the respondents.

1.12 DEFINITION OF KEY CONCEPTS

1.12.1 AIDS: Acquired Immunodeficiency Syndrome

Barker (2003:4) defines AIDS as a life-threatening, slowly progressing disease in which the HIV infects the body through contact with blood or tissues that line the vagina, anal area, eyes, and mouth or through breaks in the skin.

Thomas (1997:53) defines AIDS as the combination of specific clinical conditions and CD4+ T lymphocyte counts designated by the Centres for Disease Control and Prevention (CDC) as the final stage of infection by the HIV.

The researcher defines AIDS as a conglomeration of diseases that a person suffers, resulting from HIV infection, which has debilitating, fatal effect on the individual.

1.12.2 ARV: Antiretroviral Drug

Thomas (1997:124) defines ARV drugs as any one of the drugs used in treating patients with HIV.

Libman & Witzburg (1996:461) defines ARV therapy as specific therapy to control viral replication in the management of HIV infected patients.

The researcher defines ARVs as drugs that reduce the viral load in the blood of a person infected by HIV.

1.12.3 Compliance

Thomas (1997:425) defines compliance as the extent to which a patient's behaviour coincides with medical advice.

Oxford Advanced Learner's Dictionary (1989:237) defines compliance as action in accordance with a request or command.

According to the researcher, compliance is the act of taking medical advice according to the given instructions.

1.12.4 HIV: Human Immunodeficiency Virus

HIV is the AIDS virus, which attacks the body's immune system and thereby leaves the HIV infected person eventually vulnerable to a debilitating or fatal opportunistic infection, cancer, or neurological condition (Barker 2003:203).

Thomas (1997:915) defines HIV as a retrovirus of the subfamily lenti-virus that causes AIDS.

The researcher defines HIV as the virus that attacks and weakens the immune system of an infected person, resulting in fatal opportunistic infections.

1.12.5 Socio-Economic

Socio-economic is the categorisation of people according to specified demographic variables, such as level of income or education, location of residence and value orientation (Barker, 2003:411).

According to Thomas (1997:1781), socio-economic is the combined social and economic level of individuals or groups. Such classification is useful in studying the relationship of income and living conditions.

The researcher states that, socio-economic aspects refer to those aspects that involve people's level of income, education, and their social class, which can either be low, middle or high.

1.13 CONTENTS OF THE RESEARCH REPORT

Chapter one of the research report covers the general orientation of the study. It contains the rationale for the study, problem formulation as well as the research methodology used in the study.

Chapter two focuses on the theoretical framework on HIV/AIDS, ARV treatment and compliance, ARV Programme in Princess Marina Hospital in Botswana and the socio-economic aspects involved in compliance with ARVs.

Chapter three covers the empirical findings.

Chapter four covers the conclusion and recommendations drawn from the literature study as well as from the empirical findings.

1.14 PROBLEMS AND LIMITATIONS OF THE STUDY

- ❖ According to Health Research Unit, the research population in this study: patients who had dropped out of the ARV programme, has not been researched before. As a result, there was no literature in this regard.
- ❖ Collecting data took longer than was planned for because the majority of the patients who were in the IDCC list had died. Therefore, it took the researcher longer time to identify other patients who could be included in the sample, to reach the required sample size for the study.
- ❖ During data collection, a considerable amount of time was taken doing debriefing of relatives and family members upon being 'reminded' of their loved one who had long died.
- ❖ Upon making follow-ups during data collection, the researcher found out that some of the patients who appeared in the IDCC list of patients 'lost to follow up' were actually not lost to follow up but were regular with their clinic appointments. Unreliability in records was experienced in this regard.

CHAPTER 2

THE PHENOMENON OF COMPLIANCE TO ANTIRETROVIRAL THERAPY, HIV/AIDS AND THE SOCIO-ECONOMIC ASPECTS INVOLVED

2.1 INTRODUCTION

The emergence of the disease known as AIDS in the early 1980s coincided with a period of social transition in Southern Africa, characterised by rapid political and structural change. Why this disease has captured the attention of academics, politicians, business organisations and the general public at large is related to its potential for massive social and economic disturbance. The syndrome has been portrayed as having taken on a character of malicious intent, with its destructive teleology, becoming in the minds of some observers, a 'killer disease', a 'slow plague' and a 'misery-seeking missile' (Webb, 1997:1-2).

According to Botswana Second Generation HIV/AIDS Surveillance (2003:3), HIV/AIDS marks a severe development crisis in Sub-Saharan Africa, which remains by far the worst affected region of the world. The total number of people living with HIV/AIDS in Sub-Saharan Africa by 2003 is between 25-28.2 million. As the impact of AIDS continues to threaten the African society, African leaders are mounting a large-scale response to fight HIV/AIDS, targeting all sectors.

The above source further notes that Botswana is among the 19 African nations that have established national AIDS councils or commissions personally chaired by the head of state to take charge of a multi-sectoral response to AIDS. Many factors continue to exacerbate the epidemic in Botswana. Development projects such as mining and road construction have attracted a large number of economically buoyant young men of different nationalities to various parts of the country thus bringing them in contact with

susceptible and vulnerable young women who are less economically empowered.

The biology of HIV/AIDS will be discussed, covering aspects such as primary infection, early HIV infection, intermediate HIV infection and AIDS. HIV types and sub-types will also receive attention, the focus will be on HIV1 sub-type distribution and predominant sub-types, HIV-2 and CD4 cell count.

In addition, antiretroviral therapy will be discussed and attention will be given to the goals of therapy, indications for therapy, appropriate time to start ARVs and the clinical stages. Attention will also be given to the Botswana MASA ARV Programme, as well as issues of adherence and resistance as well as the psycho-social aspects.

The psycho-social aspects will be explored, dissecting issues such as domestic violence, literacy, the social barriers to adherence, stigma and discrimination, confidentiality and disclosure as well as HIV prevention and supportive care.

HIV/AIDS continues to deplete the economic resources of households and the nation at large, hence attention will be given to the economic aspects, focussing on aspects of political commitment, literacy, poverty and financing and delivery of care for AIDS.

2.2 THE BIOLOGY OF HIV/AIDS

According to Webb (1997:3), the cause of AIDS, identified in 1993, is a retrovirus which, since 1986, has been known as HIV. The retrovirus group includes the simian immuno-deficiency virus (SIV) and the human T-cell lymphotropic virus (HTLV), which was identified in 1980. The virus, once within the blood stream, targets the CD4 T-lymphocyte cells, which constitute a vital component in the immune system, as they coordinate antibody production and all immune responses. HIV viral RNA is transcribed to DNA

within the T-cell cytoplasm. The viral DNA is then incorporated into the host's nuclear DNA. Replication of the cell also results in viral replication, possibly concentrated within the lymph nodes

The above-mentioned author further notes that the body's production of antibodies to HIV takes place in the weeks following infection (the phase of seroconversion), where approximately half of those infected suffer limited flu-like symptoms. This phase is vital in the detection of the virus in the blood stream. The compromising of the immune system occurs when a proportion of the T-cells are gradually destroyed, so affecting immune responses, but this process is by no means understood.

According to Libman & Witzburg (1996:7), as the number of CD4 lymphocytes declines, immune dysfunction eventually becomes apparent in the vast majority of HIV-infected persons. The correlation between CD4 cell count and immunodeficiency has become a valuable tool to assess progression of the disease. Some opportunistic infections are rarely seen until the CD4 lymphocyte count drops below specific thresholds. For example, cytomegalovirus retinitis and disseminated mycobacterium avium complex (MAC) infection are unusual in individuals with absolute CD4 lymphocyte counts greater than 100cells/mm³. This observation suggests that these conditions represent reactivation of latent infections in the context of severe immunodeficiency. Other HIV-related problems occur throughout the spectrum of CD4 lymphocyte counts. For example, kaposi's sarcoma (KS) is diagnosed at all stages of HIV disease.

The above-mentioned authors also state that HIV infection in the adolescent and adult is a continuum that can be divided into four phases: primary infection, early HIV infection (CD4 count > 500 cells/mm³), intermediate HIV infection (CD4 count < 200/mm³) and AIDS.

2.2.1 Primary infection

Libman & Witzburg (1996:9) point out that primary infection with HIV may be accompanied, in up to 50 percent of patients, by the acute retroviral syndrome. The syndrome is characterised by an acute mononucleosis-like illness that begins 2 to 4 weeks after viral transmission, is generally mild to moderate in severity, and lasts for 1 to 2 weeks. The most common features of primary infection are fever, lethargy, lymphadenopathy, pharyngitis, a truncal macularpapular rash, myalgia, and arthralgia. Headaches, photophobia, and diarrhoea can also occur. In addition, various neurological manifestations, including headache, photophobia, meningoencephalitis, myelopathy, peripheral neuropathy, and Guillain-Barre syndrome, can also occur.

Several authors, (compare Libman & Witzburg, 1996:10; Bartlett & Gallant, 2004:3) agree that the clinical manifestations of primary HIV infection are:

❖ General

- Fever
- Lymphadenopathy
- Lethargy
- Myalgia
- Arthralgia

❖ Gastrointestinal

- Pharyngitis
- Diarrhoea
- Nausea or vomiting
- Hepatosplenomegaly
- Oral thrush

❖ **Neurologic**

Headache
Meningoencephalitis
Peripheral neuropathy

❖ **Dermatologic**

Truncal maculopapular rash
Mucocutaneous ulcers

❖ **Other**

Thrombocytopenia
Leukopenia
Increased liver function tests

The researcher notes that, the symptoms in the primary infection phase are often ignored as they are most of the time mild and the patient may think it is something that will clear up with time. As a result, treatment is often sought late when the immune system has suffered some damage. For this reason, education on HIV/AIDS becomes vital.

2.2.2 Early HIV infection

Libman & Witzburg (1996:11) allude that early HIV infection is characterised by CD4 count lymphocyte counts in the normal range ($>_500$ cells/mm³). The majority of individuals in this stage of infection have no symptoms of HIV disease. When clinical features are present, they most often include persistent generalised lymphadenopathy and dermatologic conditions, such as seborrheic dermatitis, shingles, and folliculitis. In general, manifestations of early HIV infection correlate poorly with the risk of disease progression.

The researcher notes that whereas there is no single panacea for HIV/AIDS. HIV/AIDS awareness and education remain crucial components in the fight against the pandemic. Education empowers people and puts them in a better position to take timely action when they experience symptoms of the disease. In addition, when people are aware about the disease and the symptoms, they are more likely to go for voluntary testing when they experience the symptoms.

2.2.3 Intermediate HIV infection

Intermediate HIV infection is characterised by CD4 lymphocyte counts between 200 and 500/mm³. The majority of individuals in this stage of infection have few or no symptoms. Clinical features present during early infection may worsen in severity or frequency during the intermediate stage. New problems may also develop, including constitutional symptoms, diarrhoea, recurrent herpes simplex virus (HSV) infection, and oral or vaginal candidiasis. In addition, bacterial infections involving the sinuses, respiratory tract, and skin become more common during this stage (Libman & Witzburg, 1996:11).

The use of zidovudine (ZDV) during intermediate infection appears to result in slower rates of disease progression. However, postponing ZDV therapy until the development of symptomatic HIV disease or a fall in symptomatic HIV infection does not alter the combined endpoint of time to disease progression or death. These observations suggest that ZDV therapy prolongs the intermediate stage of HIV infection (Libman & Witzburg, 1996:11).

The researcher states that patients are normally initiated on ARV therapy during the intermediate phase of HIV infection because it is during this phase that the CD4 count drops to low levels, hence the need to slow down the progression of the disease.

2.2.4 Acquired immunodeficiency syndrome

Libman & Witzburg (1996:12) postulate that AIDS is defined by a CD4 lymphocyte count of less than 200/mm³ or the presence of opportunistic diseases indicative of profound immunodeficiency. Without treatment, this stage of HIV infection is characterised by a 50 to 70% risk of developing a new AIDS-related condition or dying within 2 years. One of the most common conditions that characterises AIDS is pneumocystis carinii pneumonia (PCP). In addition, individuals with a CD4 lymphocyte count less than 200/mm³ are at an increased risk of developing toxoplasma gondi encephalitis, tuberculosis, cryptosporidiosis, salmonellas, and oesophageal candidiasis. In addition, many of the problems that characterise earlier stages of HIV infection may worsen when AIDS develops. Neoplasms such as lymphoma, KS, and invasive cervical cancer are seen more frequently in patients with AIDS.

As AIDS progresses and the CD4 cell count declines below 100/mm³, new disorders may ensue. Among these are cytomegalovirus (CMV) retinitis, cryptococcal meningitis, progressive multifocal leukoencephalopathy, and disseminated histoplasmosis. HIV-associated dementia may become an important source of morbidity, while wasting syndrome may impede recovery from the many illnesses experienced by those with AIDS. (Compare Libman & Witzburg, 1996:12; Bartlett & Gallant, 2004:4.)

According to Bartlett & Gallant (2004:1), in an untreated patient, the median survival after the CD4 count has fallen to <200 cells/mm³ is 3.7 years, the median CD4 count at the time of the first AIDS-defining complications is 60-70 cells/mm³, the median survival after an AIDS-defining complication is 1.3 years.

The researcher notes that, some patients, if untreated, progression to AIDS can be rapid, hence ARVs play a crucial role in increasing one's chance of survival, assisting in staying healthy and productive. Seeking medical

assistance in the early stages of infection remains pivotal in delaying disease progression. In addition, it reduces hospitalisation, thereby reducing the cost of care in hospitals and reducing the burden of care in the already overstretched health personnel. This calls for the emphasis on education and voluntary counselling and testing for people to know as early as possible if they are infected or not.

2.3 HIV TYPES AND SUBTYPES

HIV infection is established by detecting antibodies to the virus, viral antigens, viral RNA/DNA, or by culture. The standard test is serology for antibody detection. There are two HIV subtypes: HIV-1 and HIV-2, which show 40% to 60% amino acid homology. HIV-1 counts for nearly all cases except a minority of strains that originate in West Africa. HIV-1 is divided into sub-types designated A to K (collectively referred to as “M sub-types) and O. Sub-type O shows 55% to 70% homology with the M sub-types. A new group of viruses labelled “N” for “new” was reported in 1998. Over 98% of HIV-1 infections in the United States are caused by subtype B, most non-subtypes in the United States were acquired in other countries, the relatively rare O and N subtypes are found primarily in West Africa (Bartlett & Gallant, 2004:5).

Several authors (compare Bartlett & Gallant, 2004:5; Doweiko, 2001:4; Essex, 2001:6) point to the following HIV sub-type distribution:

2.3.1 HIV-1 Sub-type distribution: predominant sub-types

- ❖ **A:** West Africa, East Africa, Central Africa, East Europe, Mideast
- ❖ **B:** N. America, Europe, Mideast, E. Asia, Latin America
- ❖ **C:** S. Africa, S. Asia, Ethiopia
- ❖ **D:** E. Africa
- ❖ **E:** S.E. Asia

The researcher notes that, according to research that has been done, HIV-1 sub-type C is the most virulent of all the HIV sub-types. Perhaps this explains the reason for its rapid spread and people taking ill so rapidly, hence the high number of deaths. Sub Saharan African remains in the lead in the statistics of HIV infections, AIDS related deaths and new infections.

2.3.2 HIV-2

HIV-2 is another human retrovirus that causes immune deficiency due to depletion of CD4 cells. It is found primarily in West Africa. Compared with HIV-1, HIV-2 is less transmissible (5-to 8-fold less efficient than HIV-1 in early stage disease and rarely the cause of vertical transmission), is associated with lower viral load, and is associated with a slower rate of both CD4 cell decline and clinical progression.

2.3.3 CD4 Cell Count

According to Bartlett & Gallant (2004:18), CD4 cell count is a standard test to assess prognosis for progression to AIDS or death, to formulate the differential diagnosis in a symptomatic patient, and to make therapeutic decisions regarding antiretroviral treatment and prophylaxis for pathogenic pathogens. It is the most reliable indicator for prognosis. Factors that influence CD4 cell counts include analytical variation, seasonal and diurnal variations, some intercurrent illness, and corticosteroids.

2.4 ANTIRETROVIRAL THERAPY

The development of new antiretroviral drugs, especially combination therapies, has brought hope and optimism to those who are living with HIV/AIDS. Proper use of ARV combinations can lead to longer, better quality and productive lives.

According to Baker (2003:29), we are now at crossroads in HIV therapy. As a result of the development of antiretroviral drugs that interfere with HIV replication, it is possible to suppress the virus to undetectable levels. However, it is clear that we have yet to cure this insidious infection, because as soon as the drugs are discontinued, the virus returns in 2 to 3 weeks.

The ARVs, all of which interfere with the function of key viral gene products, impair viral replication so well that the total body viral burden can be reduced to only 1 infected cell per million. But because there are approximately 10 total lymphocytes in the body, there still remain about 1 million infected cells after the application of effective ARV. These residual infected cells constitute the problem now confronting us. It is necessary to expose the cells to ARVs, because as soon as they are discontinued, viral gene expression and replication resume (Baker, 2003:29).

The researcher posits that patient's readiness to start ARVs should be thoroughly assessed in order to realise greater chances of adherence. This will also assist in the fight against resistance to ARVs. ARVs have brought hope to many lives and people's health status has improved. However, it is crucial that education and adherence counselling continue to be given. For example, some patients, when their health status improves, have a tendency to stop taking treatment, causing more damage to their immune system by so doing.

2.4.1 Goals of therapy

Clinical goals

Prolongation of life and improvement in quality of life.

Virologic goals

Greatest possible reduction in viral load (preferably to <20-50 c/mL) for as long as possible to have disease progression and prevent or delay progression.

Immunologic goals

Immune reconstitution that is both quantitative (CD4 cell count in normal range) and qualitative (pathogen-specific immune response).

Therapeutic goals

Rational sequencing drugs in a fashion that achieves clinical, virologic, and immunologic goals while maintaining treatment options, limit drug toxicity and facilitate adherence.

Epidemiologic goals

Reduce HIV transmission. (Compare Bartlett & Gallant, 2004:49; Southern African Journal of HIV Medicine, 2002:56; Southern African Journal of HIV Medicine, 2000:23; Kaiser, 2002:11.)

2.4.2 Indications for therapy

Recommendations are based on CD4 cell count, symptoms, and viral load. The CD4 count is the most important indicator for initiating treatment, according to the World Health Organisation (WHO) guidelines and that treatment is indicated for patients with a CD4 count <200 cells/mm³. Whether to initiate therapy in the CD4 stratum between 200-350 cells/mm³ is more controversial. Some studies show no benefit with initiation at this stage, and others demonstrate moderate or no benefit. Factors that influence prognosis are the viral load, CD4 trajectory, age, patient readiness (meaning likelihood of adherence) and risk (Bartlett & Gallant, 2004:49).

According to Botswana Guidelines on Antiretroviral Treatment (2002:12), there were several considerations in choosing a first line Botswana regimen. Proof of clinical efficacy as a highly active antiretroviral regimen was a prerequisite. For cost and toxicity reasons it was decided that the regimen should be non-protease inhibitor containing. Because of concerns about adherence, the regimen had to have a low pill load and be simple to

administer-twice daily dosing at most. The people of Botswana do not have regular eating norms. Therefore it was important to select a regimen that could be taken independent of food.

The researcher states that while dosing is twice daily, therefore considered to be less burdensome, other challenges pose a risk to adherence. For example, while the patient may be less concerned about the pill load and the number of times for dosing, issues of stigma and discrimination and lack of acceptance of condition can deal a stealthy blow to adherence.

2.4.3 Appropriate time to start antiretroviral therapy, WHO Guidelines (March 2004)

According to Bartlett & Gallant (2004:52), indicators for initiating antiretroviral therapy are divided into two categories, depending on whether CD4 cell counts are available or not. The threshold for initiation of therapy using CD4 count is 200/mm³. When the total lymphocyte (TLC) is used, treatment is recommended at TLC of 1200 cells/mm³ in a symptomatic patient.

2.4.4 CD4 count

- ❖ WHO stage 4 (AIDS –defining diagnosis)
- ❖ WHO stage 3 (including HIV wasting, chronic enigmatic diarrhoea, active pulmonary tuberculosis, recurrent invasive bacterial infections or recurrent/persistent mucosal candidiasis) with consideration of using CD4 counts <350/mm³ to assist decision-making
- ❖ WHO stage 1-2 plus CD4<200/mm³ (Bartlett & Gallant, 2004:52).

2.4.5 Clinical stages

- ❖ *Clinical stage 1*: Asymptomatic or persistent generalised lymphadenopathy (PGL), and /or normal activity

- ❖ *Clinical stage 2*: Weight loss <10%, minor mucocutaneous conditions, zoster <5 years, recurrent UTIs, and/or symptomatic plus normal activity
- ❖ *Clinical stage 3*: Weight loss >10%, unexplained diarrhoea >1 month, unexplained fever >1 month, thrush, oral hairy leukoplakia, pulmonary TB in past year, or severe bacterial infection, and/or bedridden <50% of days in the past month
- ❖ *Clinical stage 4*: CDC-defined AIDS and/or bedridden >50% of days in the past month (Bartlett & Gallant, 2004:52).

The researcher posits that the rate of progression from one stage to the other differs from one person to the other. It depends, among other things, on the individual's immune system prior to infection, the HIV sub-type, with progression noted to be fastest in those infected with HIV-1, sub-type C, which is the most virulent and predominant in Botswana.

2.4.6 Appropriate time to start antiretroviral therapy: Botswana guidelines

According to Botswana Guidelines on Antiretroviral Treatment (2002:17), the early days when the dictum "start early, hit hard" was the norm, long-term toxicity, problems with adherence and the risk of viral resistance argue for greater caution. Today, the guiding principle is to start therapy when it is most likely to be needed, and when patients are either having AIDS-related illnesses or they are at high risk of developing them due to their low levels of CD4+ lymphocyte cell counts. Most international guidelines and most HIV experts agree that the following two categories of HIV-infected patients should be treated:

- ❖ Patients with severe, recurrent HIV-related disease or tumour (AIDS) irrespective of CD4+ cell count as they are already symptomatic
- ❖ Asymptomatic patients with CD4+ cell counts that are consistently <200/ml as they are at increased risk of developing AIDS-related disease within a few months.

Adult patients with major opportunistic conditions related to advanced immune suppression include tuberculosis (TB), chronic diarrhoea, ancephalopathy, and recurrent severe bacterial infections. They do not include an episode of herpes zoster or persistent generalised lymphadenopathy, conditions in which the CD4+ count may be well preserved. Also HIV-infected patients previously treated for TB will not automatically qualify for treatment but will be considered for treatment on the basis of their CD4+cell levels (Botswana Guidelines on Antiretroviral treatment, 2002:17).

According to the researcher's observation, because of anxiety and fear of testing for HIV, some patients, even when they have the symptoms of HIV, delay going for a test and the end result is that they start treatment when their CD4 count has gone further down. This poses a challenge in the recovery process as some of them seek treatment at the AIDS stage.

In addition, the researcher has observed that patients who start treatment at the 200/mm³ CD4 count cut off point, tend to respond to treatment better than those who start at far lower CD4 count levels because their immune system is not severely damaged at this point.

2.5 BOTSWANA: THE MASA ARV PROGRAMME

The MASA ('new dawn') ARV programme was set up in 2001 with technical assistance from the African Comprehensive HIV/AIDS Partnership (ACHAP), a collaboration between the government of Botswana, the Bill and Melinda Gates Foundation, the Merck Company Foundation, and the management consulting firm McKinsey & Company. A team representing a wide range of expertise was put together and commissioned to develop detailed implementation plans and ultimately launch the programme. They started by commissioning a comprehensive study of the potential demand for ARVs and how well-suited the country was in terms of funds and human and physical resources to provide the treatment (UNAIDS, 2003:61).

According to Darkoh (2004:3), the MASA programme was launched in January 2002 and currently has over 17000 patients on highly active antiretroviral therapy (HAART). MASA is currently enrolling new patients at a rate of about 1000 per month. Treatment provision has been built around a 'site' model. A MASA site currently consists of treatment initiation centre (referral, district or primary hospital) supported by four screening satellite clinics. At the screening clinics, patients are assessed to determine eligibility for treatment in the MASA programme (eligibility criteria defined as, HIV positive with either an AIDS defining illness, CD4 of 200 or less, or being a child).

The above-mentioned source further mentions that eligible patients are referred for initiation of therapy at the treatment initiation centre where laboratory investigations are done and the patient is initiated on HAART. Once stable on therapy, the patient is referred back to the satellite clinic for routine follow-up and adherence support. The satellite clinics also monitor clinically by CD4 all HIV positive patients identified according to an algorithm articulated in the national treatment guidelines.

In the ideal model, this system enables all identified HIV positive patients to be tracked, managed and initiated in therapy in a calm, orderly, non-emergency manner which minimises mortality and morbidity, as opposed to only capturing patients once they are gravely ill where HAART initiation becomes a high-resource intensive emergency intervention. The hospitals act as the multiplier and by referring stable patients back to the community-based clinics, the hospitals can successfully enrol a large number of patients at fixed capacity (Darkoh, 2004:3).

The researcher points out that the challenge for the MASA programme remains reaching those people in remote areas. Currently, the ARV centres are situated in the major urban centres and villages, which remain far out of reach for remote area dwellers. The same applies to voluntary counselling

and testing centres. This brings a scenario whereby a significant number of people are deprived the necessary services owing to insufficient infrastructure and resources. Hence, the number of AIDS related deaths continues to be high.

The researcher asserts that, more needs to be done in terms of availing ARVs and voluntary counselling and testing centres to Botswana's sparse population. This would call for injection of more financial resources.

According to Darkoh (2004:3-4) the MASA programme utilizes a four-pronged follow-up strategy:

- ❖ Buddy system: All patients are strongly encouraged to select a treatment buddy (mompoti) who supports the patient and acts as alternative contact point for the health providers in the event that a patient cannot be found.
- ❖ Computerised tracking system: The MASA programme has developed a simple software system which tracks appointments, prescription pick-ups and key laboratory and clinical information. The system allows the facility to pull up a list (with buddy and contact details) of all patients each day who have either missed a prescription pick-up or appointment. Measures, including home visits if necessary, are activated to find the individuals.
- ❖ Intensive counselling: Any patient who is having difficulty with adherence receives intensive counselling which may include doing a pill count if necessary.
- ❖ Robust IEC and community mobilisation programme: This includes providing patients with relevant written and spoken information, education and communication in Setswana and English. In addition, the MASA programme has been rolling out a picture-based interactive community mobilisation tool especially suited to non-literate members of the population. This is to ensure that as many people as possible are "treatment ready" from the community and minimises valuable time

health workers will otherwise have to spend imparting basic information.

According to the researcher's opinion, if the MASA programme is to realise its goals, more resources need to be availed, especially infrastructure and personnel. The current personnel are thinly spread on the ground and they become good candidates for burnout as well as not being effective. HIV/AIDS work is stressful even under the best working conditions. The current situation of overcrowding which characterises the ARV sites countrywide is itself a source of frustration, not only to personnel, but to patients as well.

The MASA programme has been rolling out in a phased manner since January 2002 and is currently operational in approximately 17 sites. The plan is to achieve country-wide coverage by year end (total of 32 sites). Training is the key rate-limiting step, once staff and other resources are in place. CD4 and viral load testing are performed by two central laboratories in Gaborone and Francistown with samples transported in from the peripheral sites and results faxed back to the initiating facilities (Darkoh, 2004:4).

Botswana is breaking new ground, learning to deal with an epidemic that is one of the worst in the world and with distinctive features, so there are many questions needing answers. Will the drugs behave the same way in the people of Botswana as they do elsewhere? Will the side-effects be the same? Do genetic or behavioural variations make a difference? The biggest challenge in expanding the programme remains shortages of staff and specialist skills. But reaching people in villages beyond tarred roads and airstrips presents formidable challenges too. Another lesson learnt from experience so far is that programmes should not wait until everything is in place and conditions are ideal before introducing ARVs (UNAIDS, 2003:61).

The researcher mentions that the current exodus of health personnel to the Western countries, particularly nurses, in search of greener pastures, poses a formidable challenge to MASA programme. While the programme is

expanding, as evidenced by opening of more sites and higher enrolment of patients, the hiring of skilled personnel and training of the current personnel should correspond with the demand on the ground.

African Comprehensive HIV/AIDS Partnerships (ACHAP) (2003:5) states that the government of Botswana's response to HIV/AIDS is comprehensive and coordinated through a number of national bodies. The response encompasses prevention methods including, vaccine trials, prevention of mother to child transmission, condom utilisation and information, education and communication campaigns. The prevention response is linked, through voluntary counselling and testing and total community mobilisation, to treatment through programmes such as treatment of opportunistic infections and ARV therapy.

2.5.1 Challenges and lessons for MASA Programme

Future Positive (2004:21) notes the following as challenges and lessons learned so far in the Botswana ARV programme:

- ❖ It has been much harder than expected to persuade people to get tested. A lot more needs to be done to understand the cultural and psychological barriers to being tested
- ❖ It is an ongoing dilemma trying to balance the duty to help patients who are already sick with the need to prevent other HIV positive people from becoming sick
- ❖ There has been a serious shortage of trained staff. The most critical shortage is pharmacists, but every aspect of the programme is affected to some degree. Because of the risks of drug-resistance and side-effects, a lot of training is needed to enable staff to monitor and advise patients effectively. The skill sets required by the programme are still rare in Botswana and the region, and the rewards to be found in the private sector make it hard to compete for qualified people

- ❖ Community capacity, especially in areas such as peer counselling and training, is weak, and awareness of key treatment issues such as drug resistance, side-effects and the need for adherence remain low.

The researcher notes that, given the above-mentioned challenges, more needs to be done in order to win the fight against HIV/AIDS. Although the MASA programme is relatively new, drastic measures need to be taken in order to address the current shortcomings. For example, recruitment of skilled personnel and re-training of current personnel needs to be accelerated. Community awareness campaigns need to be stepped up in the area of voluntary testing and ARV awareness.

2.6 ADHERENCE AND RESISTANCE

The Southern African Journal of HIV Medicine (2002:40) mentions that adherence is a complex clinical behaviour with a wide array of clinical determinants. A useful framework is to consider the characteristics of the patient, the clinician, the regimen, the clinical setting and the disease itself. Each of these has important influence on the levels of adherence.

Poor adherence predicts virological failure but not necessarily resistance. It appears that the highest risk of resistance is with virological failure in the face of relatively good but imperfect adherence. (Compare Bartlett & Gallant, 2004:59; Kaiser, 2002:10.)

Kaiser (2002:10) asserts that a high degree of adherence is necessary for optimal suppression with Highly Active Anti Retroviral Therapy (HAART), several studies have shown that 90-95% of doses must be taken for optimal suppression, and lesser degrees of adherence are more often associated with virologic failure. Imperfect adherence is common. The reason for missed doses were predictable and included forgetting, being too busy, being out of town, being asleep, being depressed, having adverse side-effects, and being too ill. The instability of homelessness may lead to poor adherence.

The researcher notes that factors that could act as fertile ground for poor adherence need to be addressed before a patient can be initiated on treatment. The point mentioned below captures those issues.

According to Kaiser (2002:10), many predictors of poor adherence to HIV medications have been identified. These include:

- ❖ Poor clinician-patient relationship
- ❖ Active drug use and alcohol abuse
- ❖ Active mental illness, in particular depression
- ❖ Lack of patient education and inability of patients to identify their medications
- ❖ Lack of access to primary medical care or medication
- ❖ Domestic violence and discrimination
- ❖ Medication side-effects
- ❖ Fear of or the experience of metabolic and morphologic side-effects of HAART.
- ❖ Low literacy

The above-mentioned author points to the following predictors of good adherence to HIV medications:

- ❖ Availability of emotional and practical life supports
- ❖ The ability of patients to fit the medications into their daily routine
- ❖ The understanding that poor adherence leads to resistance
- ❖ The recognition that taking all medication doses is important
- ❖ Feeling comfortable taking medication in front of other people
- ❖ Keeping clinic appointments.

The researcher posits that, emotional and social support play a critical role towards achieving adherence. When patients feel loved and accepted for who they are, it lessens the burden and pain of living with HIV and having to take

medications for the rest of one's life. It says to them "you are not alone, we are with you". The road of taking ARVs is a long one and can become burdensome and daunting if one treads it alone. Man is a social being hence he needs to feel loved and accepted.

On the other hand, the researcher asserts that rejection deals a stealthy blow to adherence. Some of the destructive coping behaviours can be attributed to rejection, for example, alcohol abuse, stopping treatment, deliberately infecting others, depression, denial and suicide.

Future Positive (2004:24) states that ARVs work. They can extend the life of someone with HIV for many years. For millions of users, they have made HIV a manageable illness, like diabetes or high blood pressure. Though they work best when they are started before a person becomes seriously ill, they have brought tens of thousands of people from the brink of death. They have given health and normality back to people so weak they could not even feed themselves or get out of bed. But ARVs are demanding drugs. They cannot be taken carelessly or casually. They will not work well, they may even backfire and cause serious problems if they are not taken correctly.

The availability and use of highly active antiretroviral therapy (HAART) has dramatically altered the natural history of the disease. During the past 5 years, those with access to potent combinations of antiretroviral agents (largely in the developed world) have derived benefit of immune restoration and prolonged maintenance of good health, and reduced morbidity, hospitalisation and mortality. In parallel with these benefits, there has been increasing recognition of the central therapeutic importance and challenges and adherence to HAART (Friedland, 2004:41).

The Southern African Journal of HIV Medicine (2002:45) states that requirements of patients in terms of adherence to ARVs are very high. They are much more stringent than the best adherence levels achievable in other chronic illnesses, and are absolute in terms of virological failure being

causally linked to clinical decline. Therefore, patients should never be commenced on ARVs until they are aware of and committed to this reality. The relationship between the clinician and the patient must accommodate the needs for ongoing education, respect, and support required in such demanding regimens.

It is never necessary to start ARVs urgently in the treatment setting with the obvious exception of the post-exposure prophylaxis scenarios of mother to child transmission prevention, occupational exposure and sexual exposure such as rape. The treating doctor should restrain her enthusiasm to commence therapy and allay the patient's anxiety regarding its commencement until both are prepared to meet the adherence needs of the subsequent regimens (The Southern African Journal of HIV Medicine, 2002:45).

The above-mentioned source further postulates that patient preparedness, initially and ongoing, is the most important factor in beginning therapy, and vital to ongoing adherence to ARVs. Education regarding the illness itself, the benefits and drawbacks of ARVs, and the longstanding nature of such therapy needs to be exhaustive and ongoing. Patients should be given sufficient time to consider the personal ramifications of taking medication lifelong, as well as the associated issues of confidentiality, disclosure and social stigma that may or may not impact on their decision. Follow-up consultations with family and caregivers if possible can assist in this process.

The researcher is of the view that because the adherence levels to ARVs are more stringent as compared to those of other chronic illnesses, follow-up, ongoing education and social support are of utmost importance. In addition, supportive counselling should be given. Involvement of family members, where necessary, assists in demystifying the HIV stigma.

Paying attention to minimising side-effect profiles of individual agents and combination of drugs is vital to the success of ARVs. Some side-effects

cannot be avoided, but may be treated successfully with simple remedies. Ongoing support and education in this regard empowers the patient to take control of such events, demystifying them and allowing for earlier reporting of adverse events. The patient's knowledge of the fact that interactions may occur, in conjunction with easy access to the clinician to discuss proposed additions to the medication regimen, for example, traditional and herbal medications or drugs prescribed by another practitioner, can diminish the chance of such events occurring (The Southern African Journal of HIV Medicine, 2002:47).

The researcher points out that Botswana, being a society whose people embrace the traditional African values, cultural practices and belief systems of the African culture, the issue of interactions poses a challenge to adherence. Culture is deep and is deeply entrenched in the lives of so many Batswana people.

Furthermore, the researcher alludes that although patients receive education on interactions, some continue to use traditional medicine, resulting in them stopping ARV treatment and not coming for follow-up altogether, with some deteriorating rapidly. It must be noted however that, there are those patients who, after stopping ARV treatment, appear to be doing well while taking traditional medicine, hence the temptation to continue further with it.

The Southern African Journal of HIV Medicine (2002:47) alludes that improving adherence is an ongoing exercise, founded equally in the empowerment of the patient and the expertise and attention of the clinician. Adequate counselling about safer sex practices must be provided to encourage prevention of new infections and re-infection. Attention should be paid on an ongoing basis, to:

- ❖ Patient-related issues
- ❖ Drug regimen complexity
- ❖ Dosing regimen requiring food restrictions

- ❖ Side-effects profiles and concomitant medication interactions.

In addition, it is vital never to underestimate the role of the doctor-patient relationship and the importance of family and friends in maintaining and improving adherence. Taking medications on a strict regimen for the rest of one's life is greatly eased by having a network of supportive persons to assist one (The Southern African Journal of HIV Medicine, 2002:48).

According to Future Positive (2004:19-20), MASA's key challenge is how to ensure that the goals of the programme are met while avoiding the one risk inherent in many mass drug roll-out and which would have catastrophic consequences in the case of a virus like HIV. HIV can quickly develop resistance to the drugs that are used against it if these drugs are not used properly. Adherence, which means taking drugs on schedule, in the right doses and in the right way at least 95% of the time, is the only way to get optimal viral suppression for a long time. Without such adherence, resistance will usually develop quickly and the patient will have to try an alternative drug combination, if there is one.

The researcher notes that practical follow-up strategies should be utilised in the case of patients who are having a problem of adherence. In some instances, home visits need to be done as well as close monitoring and referrals by the MASA team involved in care. This way, the relevant professional can be alerted by co-workers of the things she needs to pay attention to regarding her patient. For example, a patient who is having social problems, such as, family conflicts is more likely to relapse and therefore needs closer monitoring and support. A multi-disciplinary approach is critical in the fight against HIV/AIDS. The importance of team effort cannot be over-emphasised.

Future Positive (2004:19-20) postulates that the consequences of widespread resistance to the limited stock of affordable ARVs would be horrific. It is every clinical worker's and health care manager's worst nightmare. Not only would

the available ARVs begin to fail in those being treated, but the new strains of drug-resistant HIV would most certainly “escape” into the general population, spelling even greater disaster down the road. The newer drugs that still worked, if any, would be too scarce and too expensive for large-scale use. A life-saving ARV roll-out could in effect turn into a mass breeding programme for even deadlier forms of HIV.

It is argued by Future Positive (2004:20) that this, more than financial considerations, is why the Botswana ARV programme has had to be planned very carefully and implemented with a caution some AIDS activists find frustrating. But unless staff and facilities are in place to educate and monitor everyone given the drugs, adequate large scale adherence cannot be ensured, and this is a risk Botswana, with 300,000 or more people infected with HIV, cannot afford to take.

It is the researcher's view that, while efforts have been stepped up to educate the general public on HIV/AIDS and ARVs, the challenge should extend to schools as well. Increasingly, people in the school going age bracket are enrolling in the MASA programme and it is a clear sign that the schools are faced with a challenge. It thus becomes imperative that when budget allocations are made, they should be inclusive of programmes and activities for HIV/AIDS in schools.

In addition, the researcher asserts that, while there are programmes targeting youth and out of school youth, it is important to underscore the fact that such programmes currently target youth in urban centres and villages, thereby leaving out the ones in remote rural areas. The researcher therefore argues that a comprehensive HIV/AIDS programme in schools will reach majority of youth.

Future Positive (2004:24) states that in an effort to minimise the problems caused by drug resistance, the Botswana government's ARV programme uses three combinations. Unless they are already seriously ill or have been on

ARVs before, everyone beginning treatment in the programme starts with one standard “first line” therapy. If they develop resistance to this combination, or have serious side-effects, they move to the second-line combination and if this fails and resistance develops again they move to the third-line combination.

According to Future Positive (2004:25) this limited choice of drug combinations is necessary to keep the variations in drug resistant strains to a minimum. If every possible combination were being used, the chances of strains developing that are resistant across the board would be much greater. But this limited choice also means that if you do develop resistance, your options are equally limited.

MASA believes there are now about 300,000 people infected with HIV in Botswana, and about 110,000 of these should already be taking ARVs. But up to January 2004, after two years of work, MASA had enrolled about 11,000 people into the ARV treatment programme. It does not sound like much, only one in ten of those who need treatment getting treatment. But given the need to avoid the deadly boomerang of mass drug resistance this ten percent is an achievement Botswana can be proud of. One cannot be satisfied until every Botswana who needs treatment can get treatment, but the obstacles to reaching this goal are daunting (Mazonde, 2004:21).

According to the researcher, the roll-out of MASA Programme has gone on at a slower pace, albeit with some success stories to show. One of the reasons that have been advanced for the slow roll-out is the reluctance of people to go for HIV testing. With the newly introduced presidentially mandated routine testing, it is hoped that more people will access ARV treatment. Under the programme, health workers are required to offer routine testing almost universally, while allowing patients to opt out of the procedure if they choose to do so.

To capture the above-mentioned point, Mazonde (2004:7) states that in order to link routine testing programme with ARV treatment, all HIV positive results are followed by CD4 tests to assess the extent of immunological compromise and to determine whether the patient is eligible for ARV therapy.

Future Positive (2004:23) notes that ARVs are powerful drugs, and like all powerful drugs they can be dangerous, especially when taken improperly. Two issues are vitally important:

- ❖ Adherence: which means taking your drugs everyday, on time, under the right conditions (for example, before or after eating) and in the correct doses. Poor adherence not only endangers the individual but by breeding drug-resistant strains of HIV, endangers everyone who might later become infected
- ❖ Side-effects: which refers to unwanted or harmful reactions to a drug. These happen to a small number of users of any drug, but are more challenging with more powerful drugs like ARVs.

The Southern African Journal of HIV Medicine (2002:41) states that the treatment of chronic disease may require lifelong behaviour change, and the potential for regression to previous stages of readiness always exists. Relapse should therefore be anticipated, even in the most adherent patients.

Bartlett & Gallant (2004:59), propose the following as guidelines for improved adherence:

- ❖ Establish readiness prior to initiating HAART
- ❖ Address common problems: knowledge and understanding of issues, deal with adverse reactions, food issues, pill burden and dosing frequency
- ❖ Use facilitators: multidisciplinary teams (nurses, pharmacists, peers, friends/relatives/partners, community based organisations)
- ❖ Use adherence aids: pill boxes, pictures, calendars, alarms, pagers

- ❖ Documentation: pharmacy records, questionnaire results, blood levels, partner.

The researcher posits that it is better to inject more resources as an effort to realise better adherence levels than to invest minimally, only for adherence and treatment goals to be frustrated. Political commitment will go a long way in ensuring that adherence and treatment goals are realised. The success of a programme is the pride of every manager and funder.

2.7 PSYCHO-SOCIAL ASPECTS

According to Cohen, Sande & Volberding (1990:5.13.1), the social and psychological problems confronting an individual with AIDS can be enormous. Certain psychosocial issues set AIDS patients apart from patients with other life-threatening illnesses. It is well-known that patients with AIDS are often stigmatised and subsequently experience social and emotional isolation. The stigma is multifaceted, and is partly due to attributes of the disease and partly to the social standing of the groups mostly afflicted.

The following are some of the factors that contribute to the psychosocial problems as noted by (Cohen, *et al.*, 1990:5.13.1):

- ❖ AIDS is a new and complicated disease that is not well understood by the general population. Well-intentioned but uninformed individuals can have unfounded fears of contagion and be restrained toward people with AIDS
- ❖ AIDS is most frequently a venereal disease. In addition, it is commonly found among intravenous drug users, who spread it through sharing “dirty needles.” Both of these issues, sexuality and illicit drug use, can raise moral issues, thereby making it easy for patients and non-patients alike to develop an attitude of “blaming the victim” for the illness

- ❖ Gay people have historically been stigmatised solely on the basis of their homosexuality. Similarly, individuals who use intravenous drugs share, at best, a public image of being troubled, difficult or frightening.

The researcher notes that HIV is stigmatised because it is transmitted mainly heterosexually, hence the tendency to moralise it and judge PLHAs. Whichever mode of transmission people get infected with HIV/AIDS, PLHAs need to be accepted and given support. Discriminating against them will only create a divide between them and their loved ones, which can prove a challenge to bridge in the course of time.

Cohen, *et al.* (1990:2-5.13.1) further assert that in addition to being stigmatised, AIDS patients must cope with the inexorable physical decline associated with the disease. Considerable psychological stamina is required after the diagnosis, since each new symptom, infection, or indication of weight loss is regarded as a sign of potential progression of the disease. Some patients become overwhelmed by hypochondria. Others may refuse to acknowledge their physical disabilities and minimise their need for care. Neurological complications, including forgetfulness, poor concentration, lack of interest and difficulty with complex tasks are common. The complications of these central nervous system deficits may further impair the patient's ability to adapt to the stresses of their illness.

According to the researcher, a patient's reaction to a new diagnosis is seen as a normal stress response: anger, shock, disbelief, denial, numbness, and fear. After diagnosis, the patient has to cope with the losses associated with progressive illness, such as the loss of financial security, loss of employment, loss of health, loss of relationships, loss of future ambitions, loss of respect and status, loss of control, loss of independence and loss of love and intimacy. The patient may experience feelings of low self-esteem, guilt, worthlessness, hopelessness, depression, anxiety and bargaining.

Cohen, *et al.* (1990:3-5.13.1) allude that AIDS patients are especially vulnerable to emotional rejection. Discrimination occurs frequently. Housing, employment, and health care are all areas in which AIDS patients are subjected to unfounded fears of contagion and prejudice. The ability of the individual to adapt successfully to life after diagnosis of a life-threatening disease depends on the following:

- ❖ Central nervous system compromise by the disease
- ❖ Personality traits and coping mechanisms
- ❖ External support
- ❖ Social stigma.

The researcher mentions that discrimination at the work place is a source of frustration for many PLHAs. Having an Employee Assistance Programme (EAP) and hiring professionals such as social workers, who can address HIV/AIDS and wellness issues affecting staff would go a long way in addressing such concerns.

An investment towards the health and general well-being of the staff is an investment worthwhile. When employees realise that their employer takes care of them, they are more likely to stay longer with that company, productivity improves and their morale becomes boosted. Increasingly, companies are realising the importance of having EAP programmes and many of them are moving in this direction, making the necessary changes and getting rid of the obsolete stereo-types.

Webb (2002:74) notes that the determinants of HIV infection encompass behavioural and attitudinal aspects ranging from those influencing the agency of individuals as determined by their individual psychological make-ups and behavioural orientations, the sociological and cultural background and surrounding in which individuals live, and the economic circumstances relevant to the individual and his surroundings.

The researcher alludes that referral to support groups will assist the patient with getting acquainted with others in a similar situation like theirs, thereby assisting with coping and acceptance. Community home based care (CHBC) groups are also helpful in providing the needed support for the patient as the members make home visits and hence play a big role in filling the gap.

2.7.1 Responses to a person living with AIDS

According to Lachman (1995:463), it is important to recognise that a person's beliefs and values decide how one responds to a person with AIDS. It is essential for physicians to become more aware and conversant with their own morality, ethics and religion in order to interact with patients in life and death situations such as AIDS. AIDS is a unique disease because attitudes towards persons thus afflicted have resulted in social and psychological stigmatisation. Moral judgment about the mode of acquisition of the disease are inappropriate and unkind. The development of empathy by the health care worker is extremely important in learning how to communicate effectively.

Furthermore, dealing with AIDS requires, above all, integrity and compassion. Mother Theresa has said, "The biggest disease today is not leprosy or tuberculosis, but rather the feeling of being unwanted, uncared for and deserted by everybody." These sentiments are applicable to HIV/AIDS (Lachman, 1995:462).

According to the researcher, during counselling, it is important to take the patient's values, beliefs and culture into consideration. For example, if the patient wants to mourn the loss of health due to HIV/AIDS according to their culture, they should be supported to do so. This will go a long way in helping them feel accepted.

2.7.2 Social barriers

According to UNAIDS (2003:31), attitudes towards HIV/AIDS can also prevent people from accessing HIV/AIDS related treatment. These include:

- ❖ Secrecy about a person's HIV status can result from people being afraid to talk about HIV/AIDS in their families or communities
- ❖ People experience stigma when they feel ashamed or are made to feel ashamed about HIV/AIDS. People may also fear that others will blame them for it
- ❖ When people living with HIV/AIDS are treated unfairly, they suffer discrimination. People may fear that their HIV status will be obvious to others if they are seen to be having treatment. This could result in loss of work or home, or their children may be stopped from going to school. Sometimes health workers refuse to treat PLHAs because they fear that they may become infected. They may also believe that they do not have sufficient technical skills to provide treatment
- ❖ Fear of stigma and discrimination can also prevent people from seeking treatment. But if PLHAs are included in family and community activities and involved in prevention, care, support and treatment work, this can be a very effective way of reducing stigma and discrimination
- ❖ The powerful punitive and discriminatory reactions of society to those with HIV infection contribute deeply and fundamentally to the suffering of HIV-infected patients
- ❖ Confidentiality is about sharing sensitive information (such as a person's HIV status) with those who really need to know. If this cannot be done, the person's consent must be obtained before passing the information to others. If people feel that their status will remain confidential, they will be more likely to seek counselling, testing, treatment and support.

The Book of Matthew chapter 7, verse 3, The New King James Version (1985:1093), says, "And why do you look at the speck in your brother's eye,

and do not consider the plank in your own eye?” This poses a challenge to society that it is not right to discriminate against those who have HIV/AIDS because there is no person who is not faced with challenges.

2.7.3 HIV prevention and supportive care

Botswana Guidelines on Antiretroviral Treatment (2002:5) state that ARVs must not distract from HIV prevention. Every contact with the patient affords the opportunity to reinforce prevention counselling. Health care workers should stress that HIV can still be transmitted even while on ARVs. The individual must also be counselled about the potential risk of transmitting drug resistance virus mutants.

Darkoh (2004:8) alludes that, “we have always been very conscious of the fact that the introduction of HAART could serve as the pebble that would once again set concentric ripples of action and re-engagement across the healthcare system and the country as a whole. At the outset of the MASA programme, we made a clear statement that giving antiretrovirals without stopping new infections would be akin to trying to mop up a floor without switching off the tap responsible for the flood. As such, the availability of treatment gave renewed urgency and priority to stop new infections so as to avoid a costly, endless and unsustainable endeavour.”

The researcher mentions that the government of Botswana has taken a laudable step in deciding to provide ARVs to PLHAs for free. It is a costly exercise, albeit worth it in the long run. Care should be taken, however, that people not take ARVs to be the ultimate solution to the scourge of HIV/AIDS. Prevention remains key.

A lot still needs to be done at individual level, household, community and national levels. Prevention should move beyond knowledge to action. The current statistics of the number of PLHAs and the rate of new infections is worrisome and is a clear indication that the battle is far from being won.

Hence, the multi-sectoral response needs to be strengthened at all angles. All the relevant stakeholders should act in unison in the fight against HIV/AIDS.

2.7.4 Confidentiality and Disclosure

Disclosure to close family members may help encourage and motivate the patient to take drugs. Informing the partner and care takers of the continuing risk of HIV transmission even while on ARVs helps to ensure that appropriate prevention action is taken (Botswana Guidelines on Antiretroviral Treatment, 2002:5).

The family should be supported in adjusting to, and facing, the many uncertainties concerning the future health and well-being of their infected family member. Counselling on adherence should be provided to both the client and selected members of the family prior to initiation of ARVs. Supportive counselling should be continued during home visits. The family should be informed about the medication schedule, monitoring requirements, ARV regimen and refills, availability of support structures and how to access them (Botswana Guidelines on Antiretroviral Treatment, 2002:5).

Botswana National Policy on HIV/AIDS (1998:12) points out that information about the HIV status of individuals should be treated confidentially, and not be normally divulged to others without the consent of the person concerned. However, the principle of shared confidentiality should be applied, that is, those who need to know in order for appropriate health and social welfare care to be provided, should be told. Family members should be involved from the outset in the management of persons with HIV/AIDS preferably with their consent. Health and social service providers should make all efforts to involve family members in the pre-test phase.

The new epidemic of domestic violence is emerging with the growing number of women infected with HIV. To minimise the risk of violence to an HIV infected woman, pre and post test counselling must include a safety plan if the

counsellor intends to notify the partner. Notification should be delayed until a plan is in place to protect the patient from harm. Further information is needed on the type and duration of partnership in which recent infection has occurred. Particularly is this important in those infected by partners in high risk group, whether they were aware of their partner's risk factors at the time of the partnership or not (Lachman, 1995:462).

Furthermore, there should be no obligation for the employee to inform the employer regarding his/her HIV status. However, where the employee feels that sharing such information with a supervisor or employer would be helpful, health and social services should assist the employee (Botswana National Policy on HIV/AIDS, 1998:12).

According to the researcher, when people realise that their information is treated confidentially, that is likely to increase the utilisation of services as well as confidence in the service providers. Confidentiality should not be confused with secrecy, as the latter is one of the causes of stigmatisation, whereas the former promotes respect of individuals and their human rights.

2.8 ECONOMIC ASPECTS

The economic aspects of illnesses are generally analysed in terms of direct and indirect costs. Direct costs encompass personal medical care and non-personal costs. Personal medical costs include expenditures for hospital services, physician, inpatient and out-patient services, drugs, outpatient ancillary services, nursing home, hospice, and home health care. These costs are generally high if hospital and nursing home care predominate in the provision of care. Non-personal costs associated with AIDS include funds for research, blood, health, education, and support services (Arno & Green, 1990:10.1.1).

Arno & Green (1990:10.1.1) further postulate that indirect costs reflect the economic loss to society and are usually measured by lost wages due to

morbidity and premature mortality. These costs are high if illness and death occur among young men and women in the peak of their earning power and their ability to contribute to society. The economic and social costs of HIV/AIDS are far-reaching. They involve the people stricken with the disease, their friends and families, the hospitals and physicians providing the care, their employers, private insurance companies and governments.

The study conducted by the Botswana government in 2000 on the macro-economic impact of HIV/AIDS predicted that over a 25 year period to 2021, the growth rate of GDP would fall by 1,5% resulting in a GDP 20% less than what it would have been without HIV/AIDS. This will be caused by 20% increase in government expenditure mainly for health and welfare. Simultaneously, government revenue is expected to shrink by about 10% through loss of young productive adults (ACHAP, 2003:5).

According to Cohen, *et al.* (1990:9.4.3), most persons diagnosed with AIDS face the following:

- ❖ An unstable financial situation
- ❖ Loss of insurance due to loss of their job after an extended period off work due to illness
- ❖ Lovers in a similar situation
- ❖ Family members far away and unable or unwilling to help.

The researcher observes that illness often leaves a previously independent person dependent on public welfare programmes, such as the destitute programme. The loss of financial freedom is often hard to accept, and for some, it triggers the onset of depression. Hence, management of such patients is critical, for example, during counselling, it is vital that the social worker or counsellor explores the patient's social support system to help provide physical care, emotional support and assistance with activities of daily living and to refer them to the existing resources in the community.

According to the researcher, the challenge becomes even greater if the ill person was a breadwinner, with dependants to take care of. Responsibilities to take care of include; rent, bills, food, clothing, medicines, transport, and insurance.

It is important to note that the current public welfare programme in Botswana where some deserving PLHAs are provided with food basket is insufficient. In many instances, patients report that their food gets finished before they get the next supply. This is attributed to the fact that, some of these patients have to share their food with their family members. The researcher questions the sustainability of such a programme especially given that government's expenditure on HIV/AIDS is already high.

Some patients loose their housing because they can no longer afford to pay for it, further exacerbating the feeling of helplessness and loss of control due to the illness. HIV/AIDS robs people of their dignity.

The researcher is of the opinion that the need to adjust to a life of being a dependent is not always an easy one. Not knowing where your next meal will come from, who will pay school fees for your children and buy them school uniform, fear that your electricity and water may be cut off any minute due to the arrears owed, that the landlord might evict you any minute and fear of the loss of a job are insurmountable challenges that a person living with HIV/AIDS faces.

Whiteside & Sunter (2002:71) posit that although most proximate causes of being infected are biological, a person's sexual behaviour is determined by the number and type of sexual encounters he will have. Sexual behaviour is in turn determined by economic, social and cultural factors. For successful control of the epidemic, interventions are required that address the socio-economic environment and make it possible for people to change their behaviour. If prevention is to move beyond knowledge to action, we must look at the socio-economic causes of the epidemic and intervene accordingly. In

most African countries, it is recognised that HIV prevention and AIDS mitigation require a multi-sectoral response.

Mhone (2002:71) states that the complexity for HIV spread is not to be underestimated. Many of the reasons for the failure of prevention programmes to date lie in this oversimplification, in reducing the epidemic to medical and health terms, to talk of HIV/AIDS as if socio-economic processes were merely incidental. The fundamental questions have yet to be addressed, particularly those that relate to the interaction of socio-economic factors with social behaviour and attitudes as mediated through individuals, households, and communities. In this respect, issues related to poverty, fatalism, uncertainty, violence and the lack of access to crucial resources loom large.

Furthermore, the above-mentioned author notes that a comprehensive approach to addressing the HIV/AIDS epidemic, at least in the economic aspects, needs to incorporate measures that address the socio-economic risk factors, the negative demographic factors and economic consequences of the epidemic, the efficient and effective deployment of measures to prevent the infection and spread of the disease, and facilitating the treatment and care of those infected.

USAID (2002:82) point out that, regarding the issue of incidence of the cost burden, issues have been raised regarding the need to explicitly assess the degree to which the burden of managing HIV/AIDS is shared among individuals, households, communities, the private sector, the public sector and donor agencies. Among other issues, the problem of the capacity of households and the state to bear the cost of various measures becomes an important consideration. For countries with low per capita incomes and high prevalence rates the cost of managing HIV/AIDS, while morally justifiable and desirable, may be practically impossible to accommodate in the absence of external aid.

According to the researcher, HIV/AIDS has a direct impact on the individual's resources, family, community and the nation at large. Once a person is infected with HIV, it calls for them to make some adjustments in their budget and spending. This at times means depriving other members of the family of things they would normally have. Issues such as budget or finances can be discussed during counselling in order to assist the PLHA and family to accept the change and ways they could go about implementing the change with minimal upsets.

2.9 POLITICAL COMMITMENT

The range and projected magnitude of psycho-social impact of AIDS indicates that the epidemic should now be regarded as a national crisis, and receive from each government ministry, and sector of society, the attention that such a crisis deserves. All sectors and ministries, parastatal organisations, the private sector, and relevant non-governmental organisations should therefore develop and implement their own HIV/AIDS prevention activities, with initial technical support from the Ministry of Health (Botswana National Policy on HIV/AIDS, 1998:4).

Botswana National Policy on HIV/AIDS (1998:14) states that HIV/AIDS prevention activities should be integrated into ongoing activities of ministries and organisations, in order to maximise the use of existing manpower, financial and other resource. However, in order to develop the extensive and intensive programmes necessary to have significant impact on the HIV pandemic, additional resources will be needed. The government will, if necessary, increase funding for HIV/AIDS prevention and care activities to be implemented by various sectors including NGOs. This will include provision for additional key staff who will develop and coordinate the activities of various ministries and organisations.

According to Lachman (1995:527), there is a need for a prudent political arrangement for the health care arena, one that preserves simplicity in

authority and decision-making. A health care system should be created that respects the dignity of all persons by guaranteeing a right to a basic level of health care, that shelters the inherently worthy activity of caring for others, and that serves the needs of those who are less well-off.

The economic and political situation of a country also affects access to HIV/AIDS-related treatment. The poorest countries have the heaviest burdens of illness and HIV/AIDS can make existing difficulties even worse. It is much harder for people to resist infections if they do not have adequate physical and financial security, food and education. If there is an overall lack of money, both nationally and individually, there are fewer funds for care and treatment (UNAIDS, 2003:34).

In addition, the above-mentioned author asserts that political will, which involves leaders deciding to make HIV/AIDS a priority, can drive action on access to HIV/AIDS-related treatment. This often depends on commitment from the most senior people in power, from presidents to community leaders. Political will can change official priorities for health care and is also important for reducing stigma and discrimination.

According to the researcher, many developing countries, especially in sub Saharan Africa, are faced with the alarming statistics of PLHAs, new infections and deaths. Added to this challenge is the ailing economies, with civil wars, corruption and natural disasters having taken their toll on the economies. For some countries, while they realise it is morally right to provide health care to their people, it remains a pie in the sky, given the state of the nation's coffers. This leaves developing countries having to depend on donor aid and loans, plunging them further into debt.

The researcher further postulates that, when one looks at the MASA programme, the question that immediately comes to mind is the sustainability of the programme. Currently, all PLHAs receive ARVs for free in government hospitals, regardless of whether they have medical insurance or not. In order

to minimise cost on their part, many people have enrolled in the government programme. Education in Botswana has been free for many years, until recently when government re-introduced school fees, raising issues of sustainability of free education.

When the researcher juxtaposes the two above-mentioned scenarios, the researcher wonders, on the same token, whether the same plight would not befall the MASA programme. While there is foreign aid towards the programme, it should be noted that government contributes significantly to the programme. Is Botswana not likely to see an introduction of treatment fees in the MASA programme in the long run? The effect that this might have on PLHAs could pose even greater challenges in the nation's fight against the pandemic.

The worst-case scenario is that some people would most likely drop out of the programme owing to issues of affordability, while some might go for treatment only when they can afford it. This poses challenges of compliance and resistance to ARVs, hence the general decline in the health of the people, leading to decline in productivity, increased deaths, helplessness, hopelessness and despair.

2.10 LITERACY AND POVERTY

There are links between HIV infection and substance abuse, other STIs, tuberculosis, sexual abuse, and more broadly low literacy, poverty and group marginalisation. Poverty is a key factor contributing to the AIDS epidemic, according to the first full-scale report of the WHO Global Programme on AIDS (GPA). Financial hardship leads men to leave families to find work, promotes drug use, and makes prostitution a survival strategy for women with children (Lachman, 1995:532).

Botswana National Development Plan 9 (2003/2004:25) indicates that although the 2000 study on the 'Macro-Economic Impacts of HIV/AIDS in

Botswana' has not been able to provide precise estimates on the magnitude of the impact of HIV/AIDS at the house hold level, it predicts that in the long term, with the current prevalence rates, the proportion of households below poverty datum line will rise by 6%, while that of poor individuals will rise by 4%. It predicts that the national income dependency ratio will rise from 5.4 to 6.4, that is, every income earner can on average expect one extra dependent as a result of HIV/AIDS over the next ten years.' Unless government continues with HIV/AIDS social programmes, the situation is expected to be worse for the poorest 25% of the households, where 'every income earner in this category can on average expect an extra 8 dependents as a result of HIV/AIDS.'

According to Botswana Vision 2016 (1997:49), effective measures must be put in place to provide income-earning opportunities for those who are not sharing in the national prosperity, and thereby to reduce the degree of income inequality in Botswana. These must include initiatives in a variety of economic activities such as agriculture or manufacturing. This underlies the importance of building up the small and medium sized enterprise sector of the Botswana economy that will be a crucial source of employment.

The reduction of poverty is necessary on moral grounds alone. Recent research has however shown that it is sound economic strategy in the medium to long term. Poverty reduction must therefore be placed centrally in Botswana's overall development goals. Poverty has long been inherent in Botswana's socio-economic structure and cannot be treated as merely a result of drought and unfavourable climate. Natural disasters do however tend to increase poverty, and must be treated through temporary assistance. The basis for poverty reduction in the long run must be the continued existence of the main pillars of the Botswana society: peace, democracy and prudent financial and economic management (Botswana Vision 2016, 1997:50).

The above-mentioned source further mentions that the provision of social services supporting the development of human capabilities must continue, be

improved, and be increasingly directed towards the poor. Women, especially female-headed households, suffer the highest levels of poverty. They are vulnerable, particularly in rural areas, as a result of their poor resource base and limited levels of education and training. Poverty reduction policies must ensure that marginalized households have access to them.

Botswana HIV/AIDS and Human Rights Charter (2002:8) mentions that HIV/AIDS education and prevention programmes need to focus on empowering women. In Botswana and all over Africa, young women are especially vulnerable to the HIV/AIDS epidemic, and many more women are being infected than men. Women should be treated as equal partners in decision-making, especially in matters of sexual relationships. Women have the right to negotiate safer sex and condom use in marriage.

The researcher points out that low literacy levels and poverty are linked to the spread of HIV/AIDS. For example, a poor person is at a greater risk of engaging in unsafe sex at the expense of monetary benefit as evidenced in the case of sex workers. On the same token, in relationships, women have less bargaining power when it comes to sex. In cases of women who refuse unsafe sex, they are more likely to lose their partner, lose a breadwinner, or be blamed for being promiscuous, be victims of domestic violence and even murder.

The researcher further notes that, taking these challenges into consideration, it is clear that more needs to be done to empower women to refuse unsafe sex. Women empowerment groups should make deliberate efforts to stretch their services beyond the woman in the urban area. More women in the rural areas still need to be reached and it is these women who are greatly affected by illiteracy and poverty.

2.11 CONCLUSION

In this chapter, the phenomenon of the socio-economic implications of HIV/AIDS was dissected. Socio-economic factors remain pivotal in the fight against the pandemic and concerted effort and concerted campaign would go a long way in ensuring that the spread of the disease is curbed. The socio-economic factors discussed in this chapter include, literacy, poverty, social barriers.

Stigma and discrimination were discussed as some of the barriers to adherence and acceptance of one's HIV status. Education and community mobilisation were mentioned as one of the key tools to address these problems.

The reactions such as fear, denial, numbness and loss were mentioned, among others, and that they should be validated during counselling, and should be followed by empowering the patient to adopt the positive coping mechanisms needed for positive living.

An individual's uniqueness, value and intrinsic worth, their personality traits and coping mechanisms were given attention and should be taken into consideration when administering care. In the same breath, taking into account one's culture and belief system is of utmost importance.

The role of social support is also critical towards achieving the desired goals of adherence. Both the formal and informal forms of support should be buttressed to ensure optimised care.

Confidentiality should be practiced by the health workers as well as family members to show the patient care and support. Disclosure is critical in easing the burden of living with HIV/AIDS.

The importance of having and utilising tools such as follow-up and monitoring was mentioned. This will assist in identifying and monitoring periods of non-adherence.

Adherence to antiretroviral therapy is critical in improving the health and lives of PLHAs. It is noted that taking antiretroviral therapy should be accompanied by the necessary behaviour change, in terms of healthy eating, positive living, safer sex practices and taking responsibility not to spread the virus. HIV prevention remains key in the fight against HIV/AIDS and a lot should be done to prevent new infections otherwise the fight against the disease becomes a vicious cycle.

Political commitment was identified as one of the key factors in the fight against the pandemic. Government support will ensure that the necessary resources are availed in order to realise the programme goals on the fight against the disease.

The economic aspects feature as crucial in achieving adherence. If a patient does not have transport money, they cannot go to the hospital for treatment. If they cannot afford to buy food it will be difficult if not impossible to take medications.

The biology of HIV/AIDS was discussed. The knowledge of the aetiology of HIV/AIDS is crucial on the part of health workers because they can impart the necessary education to patients. Patients should be knowledgeable so that they can be able to make informed choices.

Finally, recommendations were made which could assist the health care workers and the managers of the ARV programme in meeting the needs of patients so as to enhance adherence.

CHAPTER 3

THE EMPIRICAL FINDINGS OF THE SOCIO-ECONOMIC ASPECTS INVOLVED IN COMPLIANCE TO ANTIRETROVIRAL THERAPY

3.1 INTRODUCTION

This chapter encompasses the research methodology, which will be described briefly, and then followed by research findings, which will be analysed according to the themes extracted from the respondents' responses and experiences. The themes have been categorized according to the questions in the interview schedule. Efforts have been made to integrate the empirical findings with the literature findings.

3.2 RESEARCH METHODOLOGY

The researcher used the qualitative approach in order to gain first-hand, holistic understanding of the phenomenon being investigated. Applied research was used because it contributes to abstract knowledge as well as offering guidance with regard to practical matters of daily social life. The research strategy that was used is phenomenology because it seeks to understand and interpret the meaning that subjects give to daily life.

The population for this study consisted of all the patients who had dropped out of the ARV programme at Princess Marina Hospital in Gaborone. Availability sampling technique was used to select the sample.

A total of twelve (12) respondents were interviewed, using an interview schedule. These were patients who were 'lost to follow-up' or had dropped out of the ARV Programme at Princess Marina Hospital, Infectious Disease Control Clinic (IDCC).

3.3 RESEARCH FINDINGS

The researcher used an interview schedule with open-ended questions in order to capture qualitative data. Communication skills such as probing and clarification were used in order to enhance the depth and range of responses. Non-verbal behaviour was also observed.

The researcher conducted the interviews and extensive notes were taken to capture data. Before the interview commenced, the introduction of the study was done as well as the purpose for the study.

In order to ensure voluntary participation and autonomy, the respondents signed the consent form prior to proceeding with the interview. The interviews took place in a private office at Princess Marina Hospital while some were conducted in the privacy of the respondents' homes. Confidentiality was ensured by seeing to it that nobody else, save the researcher and the research supervisor had access to data.

In this study, qualitative data is structured in the format of an interview schedule. The themes addressed are highlighted and addressed in the relevant categories and sub-categories.

3.3.1 Central themes

The respondents' responses and experiences are analysed according to the themes used in the interview schedule.

3.3.1.1 The time respondents got to know their HIV status

Data indicates that majority of the patients tested between the years 1998-2003, with majority of the patients testing in 2003, a year after the Botswana ARV Programme commenced.

“The number of centres has increased over the years. Whereas in 2000 only 3 centres were opened, they had increased to 16 in 2003. A total of 35 723 persons made one or more visits to these centres between January 2003 and 30 September 2003. Of those, 34 439 were tested for HIV” (Botswana Second Generation HIV/AIDS Surveillance, 2003:36).

According to the researcher, people have a reason to test and stay alive by taking ARVs, by utilising wellness programmes such as HIV/AIDS support groups, counselling services and through living positively with HIV/AIDS, eating healthy and adopting safer sex practices.

Botswana Guidelines on Anti-Retroviral Treatment (2002:40) states that apart from medical treatments, many people can reduce their risk of becoming ill by living their lives in as healthy a way as possible. Some people seem to be more susceptible than others, perhaps because of inherited genetic factors or their age. But other factors may be involved but some of these factors may be avoidable.

In addition, the Botswana Guidelines on Anti-Retroviral Treatment (2002:40) alludes that it is important that HIV-positive individuals should eat a well-balanced diet and that they should avoid infections that come through contaminated food or drink. Changes to ones diet can also improve or help one cope with some HIV-related symptoms such as mouth and throat infections, diarrhoea, nausea and weight loss.

Furthermore, Botswana Guidelines on Anti-Retroviral Treatment (2002:41) mentions that sex with a condom avoids passing on HIV infection to others and reduces the risk of contracting other sexually transmitted infections, which might harm a person already infected with HIV.

It is the researcher’s opinion that knowing one’s status puts one at an advantage of making choices, informed choices for that matter. One is in a better position to plan for their future, make the necessary beneficial and

positive adjustments relating to one's physical health, emotional health, mental health, and treatment options. Knowing one's status rids one of self-induced anxiety, worry and fear in that, because a person knows his status, he can seek assistance to cope or live positively with HIV through counselling intervention.

The researcher observes that since ARVs have been made available, there has been an increase in the number of voluntary counselling and testing centres as well as the increase in people testing for HIV.

In addition, the researcher posits that with more people knowing their HIV status, one would expect the stigma on HIV/AIDS to go on the decline. Interaction amongst HIV positive people can be encouraged at the IDCC through creating a forum where patients share their stories on living with HIV/AIDS. This could benefit, among others, those patients who are at a point of despair and hopelessness. Living with HIV/AIDS need not be a lonesome journey anymore with so many people living with the disease now.

3.3.1.2 Reasons for testing

Research data indicates that respondents tested because they were experiencing symptoms such as mentioned below:

'I was suspicious that I could be infected with HIV because my skin started to change, I developed sores that were taking a long time to heal.'

'I was worried that people were noticing the changes in my weight. I had lost appetite and lost a lot of weight.'

'I had body pains and genital warts.'

'I was diagnosed with diabetes, and low blood pressure. I was feeling dizzy constantly.'

'I had heard on the radio that persistent cough and fever could be a sign of HIV infection.'

'Ke ne ke lwala mme Modimo a mpolelela gore ke itlhatlhobe mogare, gape ke ne ke batla go nna le ngwana.' ('I was sick and God told me to test. I also wanted to have a child.')

'Ke badile mo bukeng gore herpes zoster ke dingwe tsa dikai tsa mogare. Ke ile ka tshoga, mme ka batla go tlhomamisa ka go itlhatlhoba.' ('I read that herpes zoster is one of the symptoms of HIV/AIDS, I wanted to confirm this by testing.')

'I went to the clinic and was diagnosed with a sexually transmitted infection. I had had vaginal itching and discharge for some time.'

'For a long time, I suffered epigastric pain and had mouth ulcers.'

'For some time, I was feeling weak. I started to have insomnia and was depressed.'

The above captured data was reported by the patients themselves and was not taken from their medical files. The data indicates that majority of the patients experienced the problem of loss of weight and appetite as well as anxiety and fear as to what the symptoms they were having meant. According to their account, they were worried that *'I am starting to look different and therefore people might suspect that I have HIV'*, hence the decision *'go ntsha pelo pelaelo'* ('to confirm my fears') by testing.

According to MASA Antiretroviral Therapy (2004:5) one of the interviewees in the study for the MASA project stated that, "most people are afraid and it is scary. Not knowing my status was worse than finding out my positive status. Not knowing breeds doubt and that steals your happiness. Catching AIDS

was like a traveller crossing the Kgalagadi Desert without any water. Knowing ones status is important because it helps one to plan effectively.”

Van der Ven (2002:38) postulates that, some opportunistic infections occur when the patient is still in a relatively good condition. If a patient presents in this manner, it may be a good time to talk about HIV, so that the patient can receive follow-up and be given ARV treatment should the patient fulfil the necessary criteria.

The researcher notes that early intervention in seeking HIV treatment is beneficial if one meets the criteria for treatment. This will ensure that damage to the immune system is halted, thus one can enjoy prolonged life and live to realise their goals and dreams.

Furthermore, the researcher points out that it is clear from the respondents' responses that none of them went for HIV testing on their own accord, in other words, they were forced by circumstances. They tested because they were experiencing symptoms that made them suspect that they could be infected with HIV.

What is important to note however, is the fact that most of them had received information on HIV/AIDS and thus, they were aware of the symptoms of the disease. It is this prior knowledge about the symptoms of HIV/AIDS that caused them to seek medical assistance. Clearly, the importance of education cannot be understated.

Botswana HIV/AIDS and Human Rights Charter (2002:6-7) mentions that all persons have the right to comprehensive education about HIV/AIDS, prevention methods and reproductive health, they have a right to information regarding all available treatments including antiretrovirals and clinical trials.

The researcher is cognizant of the fact that because of fear, people delay testing for HIV. It would be worthwhile that during medical visits, patients

receive HIV/AIDS education. If people are ignorant about something, they are not likely to do anything about it, unlike if they are aware. Ignorance can be deadly while education is power. HIV/AIDS awareness should target all population groups, while being sensitive to the varying needs of the different population groups, for example, school going youth, out of school youth, adults, et cetera.

The researcher observes that, since the inception of the Botswana ARV Programme in 2002, the number of people who are taking ARVs is continually increasing. This bears testimony to the fact that more people are testing for HIV. As a result of people seeking treatment in the early stages of HIV, they are enjoying improved health.

To illustrate the above-mentioned point, the researcher gives the example of Gaborone ARV site as stated in MASA Antiretroviral Therapy (2003:6) that, in July 2003; 4 517 patients were on ARVs as compared to the current figure in MASA Antiretroviral Therapy (2004:8) that, in June 2004; 6 784 patients had enrolled in the programme.

The researcher posits that as people see the positive results of taking ARVs, more people are likely to go for testing, hence enrol in the ARV Programme. It is important to note that ARVs alone are not the solution for HIV/AIDS. They need to be accompanied by positive behaviour change in relation to issues such as stress management, healthy eating, safer sex practices and positive living.

3.3.1.3 Respondents' feelings when they were diagnosed

The responses given by the respondents varied and majority of them pointed to the fact that they were already suspicious that they could be HIV positive based on the symptoms they were experiencing. Their responses are mentioned below:

'I was not shocked when diagnosed HIV positive because I had been suspicious of the symptoms I was experiencing.'

'I wanted to live longer.'

'I was afraid when I was diagnosed HIV positive but not badly because I had told myself that there is a possibility that I could be HIV positive because of the symptoms I was having.'

The researcher infers that the above-mentioned responses attest to the fact of widespread education on HIV/AIDS. It shows from the responses that the respondents were aware of the HIV symptoms. They had some degree of knowledge on HIV/AIDS.

One of these reported that she used to joke about it at work that she is HIV positive although she had not tested then, thus when she tested HIV positive, *'seo se ile sa rurifatsa pelaelo yame'*, (*'that confirmed my suspicion.'*) *'I was happy to start ARVs because I wanted to regain my health.'*

'I was hopeful that I would recover, I accepted the diagnosis because I had asked God for strength. I believed that God would heal me.'

'I was shocked. I was counselled for some time for denial and stress. I was depressed. I felt hopeless when diagnosed.'

The other feelings experienced by the respondents included denial, stress, depression, fear, hopelessness, shock, acceptance, asking God for strength.

In MASA Antiretroviral Therapy (2004:6), an interview with one of the persons living with HIV/AIDS concurs with the above-mentioned symptoms. "When I found out that I was HIV positive, I felt like an outcast, a black sheep of my family. I experienced phases of denial, followed by periods when I felt cursed. I kept asking myself how it could be."

According to Linsk, Mitchell, Despotes & Cook (2002:67), despite treatment advances, HIV is associated with issues of grief and loss, disclosure to families and employers, fear, uncertainty about the future, decisions about when to start antiretroviral therapy, and potential treatment failures.

It is the researcher's opinion that increase in HIV/AIDS awareness will go a long way in helping curb the spread of HIV and reduce stigma. It will also help people take control of their health.

In addition, the researcher posits that patients should be made aware that it is normal for them to experience the varying mental and emotional reactions they experienced when they suspected that they could be HIV positive. However, it is imperative that they seek counselling to be assisted to adopt the positive coping mechanisms to deal with their situation. This is crucial because some people, when faced with a crisis or challenge, resort to destructive ways of coping such as alcohol abuse, suicide, et cetera.

The researcher notes that during counselling, the social worker or counsellor should take into account where the patient is at emotionally and mentally, hence go through the different phases of counselling. It is important that the patients' feelings be validated because even themselves, they are trying to make sense or understand why they are feeling the way they are feeling, and if left unattended, can cause emotional, physical or mental harm. It is during the crisis phase and chronic phase of HIV/AIDS disease that supportive counselling is of utmost importance, as well as crisis intervention.

The researcher points out that the social worker or counsellor should address issues of diagnosis: reaction to diagnosis, such as shock and denial. The professional should also offer emotional support and address the multiple losses the patient is experiencing and allow the patient to grieve those losses, such as, loss of health and loss of independence that could emanate from hospitalisation. The patient should be given an opportunity for catharsis and

issues of disclosure, safe sex, support systems, coming to terms with diagnosis and restoring equilibrium should be dealt with.

In addition, the researcher posits that patients often face a crisis as symptoms start to appear. Crisis intervention should be used as a model for intervention. The social worker should offer emotional support and allow for ventilation of feelings, provide education on the symptoms and the stages of HIV/AIDS. In addition, the social worker should explore if the patient is having some suicidal ideation.

3.3.1.4 Respondents' feelings when they started ARVs

The majority of the respondents indicated that they wanted to start ARV treatment. They expressed hope that ARVs would improve their health, therefore they would live longer, while others expressed fear concerning treatment side-effects. While majority of the respondents reported that they started ARVs on their own accord, others stated that they were convinced by health professionals to start treatment. The following are their expressions:

'I was eager to start ARVs.'

'I wanted to be healthy.'

'Ke ne ke na le tsholofelo ya gore ke tla tshela.' (I became hopeful that I would live.)

'I was not excited to start ARVs.'

'I believe more that God would heal me than ARVs.'

'Taking ARVs is stressful because one has to take them for life.'

'I feared the interaction between ARVs and alcohol.'

Regarding the above point, Kaiser (2002:11) alludes that, a patient with active substance abuse or mental illness may benefit from immediate psychiatric treatment or treatment for chemical dependency.

This confirms what the other respondent said regarding his intake of alcohol whilst using ARV treatment. It would seem some people are aware of the dangers of taking alcohol together with medical treatment, even though they do not have scientific facts. This calls for serious consideration when providing information, that it must be comprehensive, to equip the people to make informed decisions regarding their health.

The researcher posits that it is important that when patients seek medical treatment, they should be encouraged to disclose all the problems they are having that could pose a problem regarding compliance, for example history of drug/alcohol abuse, relationship problems, financial problems, mental illness, et cetera. In that case, such patients can be assisted accordingly by being referred to the relevant professionals for treatment or counselling intervention. This can only be achieved if the service providers are also sensitive to the needs of the patients, which calls for a coordinated multidisciplinary team effort.

In addition, the respondents stated the following about how they felt when they were put on ARVs:

'I had to hide my ARVs from my children because I had not told them about my HIV status and this stressed me out.'

'I was worried when visiting my relatives that they would see me take ARVs, they would get to know my status even though I did not want them to know.'

To underscore the above-mentioned responses, UNAIDS (2003:31) postulates that secrecy about a person's HIV status can result from people

being afraid to talk about HIV/AIDS in their families or communities. Fear of stigma can also prevent people from seeking treatment. But if people living with HIV/AIDS are included in family and community activities and involved in prevention, care, support and treatment work, this can be a very effective way of reducing stigma and discrimination.

According to the researcher, involving people living with HIV/AIDS in HIV/AIDS education and awareness can be helpful in breaking the walls of stigma and discrimination.

The above-mentioned point is captured by MASA Antiretroviral Therapy (2004:2) when it states that, 'MASA's most encouraging result is the massive increase in community awareness and engagement around ARV therapy. The large burden of the disease demands that communities become involved and provide a significant amount of service to reverse the tide of the HIV/AIDS epidemic. MASA has involved people living with HIV in patient education and community mobilisation activities. Through the buddy system, lay people have now become part of the extended health team.'

Furthermore, on how respondents felt when they were started on ARVs, their responses are continued below:

'Because ARVs are taken for life, I feared that they would make me sick.'

To capture the above-mentioned point, UNAIDS (2003:31) states that people may not access HIV/AIDS-related treatment because they have certain beliefs about the treatment. For example, they may think that the drugs would not make a difference to them or that unpleasant side-effects outweigh the benefits. Attitudes towards HIV/AIDS can also prevent people from accessing HIV/AIDS-related treatment.

The researcher notes that the above-mentioned point raises the importance of educating patients on the symptoms of HIV/AIDS; all the stages of the

disease, as well as educating them on the treatment side-effects and the importance of seeking medical treatment immediately.

There are respondents who stated that their main concern when being initiated on treatment, was the fact that they were told to eat a healthy diet, yet they did not have the finances to buy the necessary food.

'I am unemployed, therefore, I cannot afford to buy healthy food.'

To emphasise the above-stated point, UNAIDS (2003:31) points out that people living with HIV/AIDS, their families and communities often face difficult choices about the cost of treatment. For example, they may have to decide between paying for treatment and buying food or paying school fees for children.

According to the researcher, the problem of unemployment poses problems in HIV/AIDS management. While one is taking ARVs, they need to eat healthy so that their immune system can be strengthened. While Botswana government has a programme to provide foodstuff for unemployed HIV positive people, in many instances the patients have complained that their food gets finished before they get the next ration. For some, it is due to the fact that they end up having to share their food with other members of the family, while for others, cases of abuse have been reported whereby they sell the foodstuff in exchange for alcoholic beverages.

Although some of the respondents looked sick during the time of the interview, for example, had mouth and throat ulcers and weight loss, they were adamant that ARVs are not the ultimate solution to HIV/AIDS, but God is. This is illustrated by the response from one respondent:

'I know that ARVs cannot cure me, but God can, and I am waiting for my healing from Him.'

Overall, majority of the respondents reported that they were happy to start ARVs because of the hope of living longer and healthy lives that this treatment is bringing to their lives. It can be inferred from this data that the respondents knew the benefit of ARVs although that knowledge did not translate into a positive response to treatment, which could be attributed to a variety of factors impacting on the patients' efforts to comply with treatment as indicated in chapter 2 of this report.

While they had dropped out of the ARV programme on their own accord, majority of them expressed the desire to re-enrol in the programme. The researcher made bookings for them at the ARV clinic and indeed they were re-enrolled immediately. The researcher was able to identify a need during interviews, that, although the respondents had stopped taking ARVs, majority of them on being asked the question, "How did you feel when you stopped ARVs?" they expressed regret, fear and anxiety that they could fall sick again or die, they feared the health workers would be angry with them if they went back to the clinic.

It was thus clear that the respondents needed some assistance in order to re-enrol in the programme. A loophole that was identified in the system is that of lack of follow-up and monitoring. If follow-up was done, such patients could have been identified and given the necessary assistance. If compliance is to be achieved, monitoring and follow-up instruments should be given serious attention and implemented accordingly. It is clear from this example that the problem of patients who are 'lost to follow-up' need not be as big as it is now if instruments of follow-up and monitoring were utilised accordingly.

UNAIDS (2003:61) reverberates the above-mentioned view and notes that, all patients in the MASA programme are given identity numbers, and all the drugs prescribed to a patient are recorded, along with the dates when they should return for a re-supply. If the patient does not return on the correct date, it is immediately apparent.

The researcher is of the view that, the current staff shortages at IDCC are one of the contributory factors why follow-up and monitoring is not done sufficiently. More focus is put on attending the patient at the clinic and not much is done to cater for the patient outside the clinic. It is in the light of this that more recruitment should be done, as well as training of the current and new personnel.

ARVs are expensive, more so that they have to be taken for a lifetime. Thus, a lot more should be done to ensure that the patients get the full benefit of such treatment and also that the government and other sponsors get their money's worth. For example, government is hoping that ARVs would improve people's lives and health, so that they can be economically productive, ease the burden of orphans by being alive for longer and take care of their children. This rippling effect can be realised through tighter adherence controls.

3.3.1.5 Ways in which ARVs improved respondents' quality of life

Majority of the respondents reported an improvement in their quality of life while they were taking ARVs. The following are their responses:

'My weight and appetite improved.'

'Sehuba se se ne se ntshwenya se ile sa fola' ('I recovered from persistent cough.')

'When I was started on ARVs, I started to read widely on HIV/AIDS and as a result, I am able to make informed choices on issues relating to my health such as diet, safe sex, and positive living.'

'ARVs helped me when I first started taking them but now, I feel they are not helping me anymore because my health is deteriorating. I was introduced to ARV treatment by a private practitioner before enrolling on the national ARV programme. I feel changing prescriptions too many times has contributed to

my ill-health, while being treated by this private practitioner as it was done on a trial basis. He said he was changing them because I was not responding to treatment. He said everybody was learning, hence they tried the different combinations. When resistance test was done, I was found to be resistant to some ARVs.'

'My health deteriorated when I started taking ARVs, this was due to severe drug side-effects. I was feeling weak, dizzy, lost appetite and weight, and had nausea. I started to feel better when I stopped taking ARVs, and now I am taking traditional medicine. As a result of taking traditional medicine, the symptoms I had such as vaginal sores and discharge are gone, my weight and appetite have improved and I am happy about the treatment. I will never take ARVs again.'

To confirm the above-mentioned point, Kaiser (2002:11) alludes that the development of side-effects can affect the ability to adhere to treatment. Clinicians should inform patients in advance about possible side-effects and when they are likely to occur; treatment for likely side-effects should be included in the first prescription along with the instructions on the appropriate response and the possible need to contact the clinician.

The above-mentioned author further notes that in some cases, low literacy has been associated with poor adherence; clinicians should take care to assess a patient's literacy before relying on written information, and to tailor the adherence intervention to the individual patient.

The researcher notes that the respondents interviewed had low literacy levels. Majority of them had only up to secondary education, few had tertiary education, with some with no education at all. One respondent who was illiterate reported that if he knew how to read, he would never have missed the appointments. He said he no longer had anyone to tell him it was time to go for follow-up appointment after his 'buddy' died.

In addition, UNAIDS (2003:33) states that, in some countries, traditional healers have a working relationship with medical practitioners in the public and private health systems. Where this happens, it can be possible to encourage traditional healers to:

- ❖ Provide care and symptom relief
- ❖ Dispel myths about harmful practices
- ❖ Dispel myths about HIV/AIDS
- ❖ Teach people about HIV prevention and
- ❖ Refer people to health facilities.

The researcher notes that more still needs to be done in Botswana for the above to be realised. Many Batswana visit traditional healers but many do so in secrecy because they do not want to be publicly associated with them. Making the traditional healers part of the treatment team, with clearly defined roles, could improve this situation and the patients could benefit.

In addition, the researcher has observed that, some traditional healers, because of the quest for making profit, do not refer patients for medical treatment and only do so when the patient's health has deteriorated beyond turning point. Some of these traditional healers have none to low literacy skills and are based in the rural communities where HIV/AIDS awareness is already low. This brings the challenge to the relevant stakeholders of the need to bring more education and awareness campaigns amongst traditional healers and the rural communities.

MASA Antiretroviral Therapy (2003:13) notes that it is important to develop programmes to bring traditional healers on board as allies rather than as adversaries.

Other areas of improvement when taking ARVs were noted in the increase of CD4 cell count and the reduction of viral load for majority of the respondents.

In addition, the respondents reported an improvement in their health in the following areas:

'When I was taking ARVs, the sores I had been suffering from healed.'

'Sedidi sa me se ne sa ema.' ('My dizziness stopped.')

'My insomnia stopped, I could sleep well again.'

'I had mouth ulcers on and off before starting treatment, I never got them again.'

'Ditlhabi tsame di ile tsa fola.' ('The bodily pains I used to experience stopped.')

'I used to have epigastric pain, it stopped.'

'My sexually transmitted infection cleared.'

'I was able to walk again and started to have a positive out look towards life.'

'When taking ARVs, I was never hospitalised, unlike before. I even went back to work.'

It is thus concluded from this data that, overall, majority of the respondents reported an improvement in their quality of life while taking ARVs.

The researcher notes that, ARVs, if taken as prescribed, can contribute towards the general improvement of a person's life, as well as restoring good health and living longer, productive lives. Some patients have experienced restoration of hope because they are back to work or school and leading normal, active lives.

3.3.1.6 Reasons why respondents stopped going to the hospital for follow-up assessment and treatment

The respondents advanced several reasons as to why they stopped going to the hospital for follow-up assessment and treatment. Some are factors beyond their control, while some are those within their control. Their responses are noted below:

'I stopped taking ARVs because my health deteriorated, I did not see the improvement in health that I expected.'

'AIDS is too complicated for human beings. The best solution is to look up to God for healing because all strength comes from God. I do not rule out the possibility of starting ARVs again, if God tells me it is okay to do so. I am not on any medication now, however, I am praying for my healing.'

'I stopped ARVs because I feared Infectious Disease Control Clinic (IDCC) staff would be 'mad' at me for falling pregnant. I felt shame and that people would wonder, 'why did you fall pregnant when you are HIV positive?' I had enrolled in the Prevention of Mother to Child Transmission Programme (PMTCT). I thought I was on the safe side and therefore made a decision to stop going to IDCC at eight months of pregnancy when I started PMTCT.'

Kaiser (2002:12) postulates that provider attitudes and behaviours that are supportive and non-judgmental will encourage patients to be honest about their adherence and about problems they have experienced with adherence.

The researcher notes that to encourage compliance, follow-up strategies should be devised that will target patients who are less-likely to adhere to treatment, for example, home visits can be done as well as phone calls. Monitoring may help identify periods of non-adherence.

MASA Antiretroviral Therapy (2004:6) concurs with the above-mentioned point and mentions that for any new programme that is about to start, the highest priority and bulk of initial effort should go towards establishing a robust and reliable monitoring and evaluation system. With this in place, a country is allowed many more degrees of freedom in experimenting with different models of service provision: community outreach worker models, traditional referral models, observed therapy models, et cetera, with the reassurance that any emerging problems can be quickly identified and addressed.

In addition, Kaiser (2002:12) asserts that interventions that have been associated with improved adherence include a pharmacy-based adherence clinic, a street-level drop-in centre with medication storage and flexible hours for the homeless, an adolescent-specific adherence training programme, and medication counselling and behavioural intervention and for all health care team members, specific training on Highly Active Anti Retroviral Therapy (HAART) should be offered and updated regularly.

The researcher points out that periods of non-adherence differ from patient to patient and are triggered by different factors. It is clear from some of the responses that more should be done in encouraging patients to report factors that they feel could contribute to non-adherence such as pregnancies, alcohol abuse, et cetera.

In addition, although a patient is starting on some other treatment regimen from another medical practitioner, they should always consult their doctor before doing so or let the doctor know of their intention to stop treatment. Doing this will ensure the patient gets the necessary advice and counselling regarding the action they want to take.

The researcher is of the view that when the patient is aware of the dangers he is getting himself into by stopping treatment, they will be less likely to do so,

compared to if they did not know. This way, the patient can make an informed choice. Thus the problem of non-adherence can be curtailed.

Kaiser (2002:12) notes that there is evidence that adherence wanes overtime, even in highly adherent patients, a phenomenon described as “pill-fatigue” or “treatment fatigue”. Thus monitoring adherence at every clinical encounter is essential.

In addition, the respondents gave the following reasons for stopping treatment:

‘I feared to come to IDCC because I thought they would not accept me back.’

‘Because I am illiterate, I never know the date for appointments. I used to be assisted by my wife in this regard before she died. Nobody in the family is literate. I only go for appointments if the local clinic counsellor reminds me. I have never come to IDCC on my own. I always rely on local clinic transport because I have no money. I have tried to look for a job, but to no avail. Ke monnamogolo.’ (‘I am an old man.’)

The researcher postulates that with regard to the problem of illiteracy, because studies have shown that people with lower literacy levels are less likely to adhere to treatment, more should be done to cater for them. For example, they could benefit from closer follow-up and monitoring from the IDCC personnel.

Age is another critical factor. The older patients would benefit from even tighter adherence controls because due to illiteracy, poverty, and aging taking its toll on them, they can be prone to non-adherence.

Furthermore, the problem of lack of transport money has also been identified as one of the factors that contribute to non-adherence. The researcher notes that, with the opening of more ARV sites, it is hoped that such problems will

be addressed because services are being brought closer to the people. The challenge still remains though, especially for people in remote rural areas. The proposed ARV sites would still be far from them. They would benefit from closer monitoring.

Unemployment remains one of the critical factors to compliance especially if there is no breadwinner in the family. IDCC and other HIV/AIDS organisations should be hailed for continuing to provide employment to PLHAs. They are leading by example in this regard that PLHAs have a right to employment like everybody else.

However for those patients who are facing unemployment problems, government could improve the situation by more employment creation as well as making the citizen empowerment programmes such as Citizen Entrepreneurial Development Agency (CEDA) to be within reach to even the lowliest member of society because they too, need to earn a living.

The researcher notes here that some people do not have the start-up capital required to embark on such businesses, which means they are automatically left out. Such inequalities need to be addressed especially taking into consideration problems such as HIV/AIDS. PLHAs need to have their basic needs of clothing, food and shelter met and for most of them, this can only be realised if they are have some employment.

Botswana HIV/AIDS and Human Rights Charter (2002:9) notes that PLHAs have a right to work. HIV/AIDS testing should never be a requirement for employment. Workers with HIV/AIDS should be treated the same as other workers. They should have equal employment benefits and rights, for example, confirmation on the job, education, training and promotion.

The researcher questions the sustainability of the current assistance by government of giving some PLHAs who meet the criteria, some food rations. Long-term strategies should be the way to go while at the same time being

cognizant of the dependency syndrome. It thus becomes critical that self-reliance should be inculcated into people while at the same time providing for them the necessary resources to realise this.

'I could not come to the hospital because I was very weak and could not walk. Although I was still getting my salary, I could not afford to hire transport anymore as I was broke and some of my relatives squandered my money. Both my parents are sick and I am the one financially supporting them, as the sole breadwinner in the family.'

'I stopped coming to the hospital for treatment because of congestion at the IDCC clinic.'

'The pharmacy queues are too long and there are few doctors.'

'I stopped coming to IDCC because as an employee, I was losing time at work because of spending all day at IDCC.'

'I did not get satisfactory assistance when making enquiries at IDCC. I was referred by a private practitioner to the IDCC. I was tossed from pillar to post and because HIV is a secret, I couldn't stand such treatment. Also, I lost my job and had to relocate to my home village where there was no ARV clinic.'

According to the researcher, problems of stigma are a big challenge for PLHAs. The secrecy that surrounds HIV/AIDS diagnosis seems to compound this problem further. People readily disclose other illnesses that they are suffering from, but not so with HIV/AIDS. Having more people go public about their HIV status can in part address the problem of stigma as well as patient education.

Taking the already existing stigma around HIV/AIDS into account, it is imperative that health workers be sensitive when dealing with patients. The researcher here does not suggest that health workers should help further

compound the stigma problem but rather that, how health workers handle patients can either assist in encouraging patients to continue utilising the services or turn the patients away. The customer is king.

Furthermore, the researcher notes that in health facilities, patients should be treated with respect and care because some of them are suffering from depression emanating from their illness or have already suffered discrimination in the hands of co-workers or family. It is thus imperative that health personnel be warm and welcoming to patients while being sensitive to their unique and varying needs.

While the researcher notes that service at the IDCC is good in general, there is always room for improvement. For example, patients can be accorded more dignity and respect in the way they are treated and talked to. The researcher has observed that the stress levels at the IDCC are high amongst staff members, hence, their frustration is sometimes displaced on the patients, albeit wrongly so. The Princess Marina Staff Emotional Support Group can be of tremendous assistance in this regard.

The patient-staff ratio is high. As a result, life at the IDCC is characterised by queues without end. To add to that, the building proves to be very small now because more patients are continuing to be enrolled. The congestion is too much, as indicated by the respondents, they are discouraged to go to the clinic because of the long queues.

The staff at the IDCC have been trained for their various jobs but because they are working under tremendous pressure most of the time, they are more likely to render unsatisfactory service all because they are more focused on clearing the queues before the day ends. Hence, quality is compromised at the expense of quantity. The researcher is of the view that if more personnel can be hired, there would be a much greater improvement in service delivery.

‘ On several occasions, I was told my laboratory results were not available.’

'Coming to IDCC is a hassle because each time I come, my vital signs are checked. I feel it is unnecessary. I am anxious when at IDCC because I do not want to be seen by other people that I am taking ARVS. I was seen by somebody I know at the clinic and I almost fainted! I do not want people talking about me.'

With regard to the above point, UNAIDS (2003:31) states that, people experience stigma when they are ashamed or made to feel ashamed about HIV/AIDS. People may also fear that others will blame them for it. When people with HIV/AIDS are unfairly treated, they suffer discrimination. People may fear that their HIV status will be obvious to others if they are seen to be having treatment. This could result in loss of work or home, or their children may be stopped from going to school.

According to the researcher, more can be done to see to it that adherence levels are improved and this will require concerted effort as well as an overhaul of the current policy and strategies that are not practical. Monitoring and evaluation tools should be fully utilised. Monitoring is not sufficiently done, it is not given the priority that it deserves because the staff are overstretched. Hence, other duties take priority.

What the researcher found disturbing was that there was no tool in place to monitor the number of deaths that have occurred or if it was there, it was not being utilised. The clinic relied on relatives reporting such deaths. However, not all of them come to report the deaths.

The researcher was faced with an enormous challenge in getting the number of respondents required for this study. While the list of patients 'lost to follow-up' obtained from IDCC was long, the researcher was in for a great shock, majority of those patients had long died! It was a stressful and tedious exercise because the researcher now had to address the emotional reactions

of the relatives on being reminded of their loved one who long died. It was touching.

What transpired during the study was that, when the researcher made telephone contacts and home visits according to the list of patients who are 'lost to follow-up' that she got at the clinic, she found out that majority of the patients in that list had died, some as far back as 2002, not long after the programme started and 2003, yet the clinic did not have record of such.

Some patients could not be traced at all because they had either changed their address or were not known at the address they gave. It is thus apparent that there is gross under reporting of deaths. A system to address this need, needs to be put in place, or if it is already there, it needs to be put to use.

IDCC staff should conduct research studies so that they can be able to identify the needs and challenges that the clinic is faced with. This will assist in the betterment of services. Having a suggestion box can also be of assistance in this regard.

3.3.1.7 Reasons that led to respondents not taking treatment as prescribed

In this study, several factors have contributed to the respondents not taking treatment as prescribed. Their expressions are mentioned below:

'I have been praying and believing God for healing.'

'I am tired of taking pills daily, I don't like taking pills, and I was taking them because I had no choice.'

'I was experiencing unbearable side-effects.'

'There are too many patients at the clinic. I fear that people will see me at IDCC and start to talk.'

'The congestion at IDCC is a turn-off!'

'I did not know the date for check-up'

According to Kaiser (2002:10), many predictors of poor adherence to HIV medicines have been identified. These include:

- ❖ Poor clinician-patient relationship
- ❖ Active drug and alcohol use
- ❖ Active mental illness, in particular depression
- ❖ Lack of patient education and inability of patients to identify their medications
- ❖ Lack of reliable access to primary medical care or medication
- ❖ Domestic violence and discrimination
- ❖ Medication side-effects
- ❖ Fear of or the experience of metabolic and morphologic side-effects of HAART.

In addition, MASA Antiretroviral Therapy (2004:1) alludes to the following factors as the cause for poor adherence:

- ❖ Alcohol use and abuse
- ❖ Not informing relatives and employers about ARV therapy, therefore, taking medication in secret
- ❖ Travelling out of base
- ❖ Cost of transport

MASA Antiretroviral Therapy (2004:1) continues noting that, 'some patients are so impoverished that they simply cannot always afford to travel to the clinic when they have appointments.'

The researcher points out that, some studies have found that with time, patients tend to experience 'pill fatigue' and because ARVs are taken for one's lifetime, there needs to be some strategy in place to address such a problem because even the most adherent patients have been found to have periods of non-adherence. At IDCC, the doctor checks adherence through asking the patient. Tests such as CD4 cell count and viral load are done to assist in determining adherence, among other things. Pill counts are done at the pharmacy.

As far as the researcher is concerned, there should be adherence specific on-going counselling and education for already existing patients. Currently at IDCC, most of the education on adherence counselling is done during the first visit. Because standardisation is important, a questioning tool can be designed to address this and then relevant counselling given. In addition, a patient education leaflet should be developed that focuses on adherence and related issues.

Kaiser (2002:10) identifies predictors of good adherence as follows:

- ❖ Availability of emotional and practical life supports
- ❖ The ability of patients to fit the medications into their daily routine
- ❖ The understanding that poor adherence leads to resistance
- ❖ The recognition that taking all medication doses is important
- ❖ Feeling comfortable taking medications in front of people
- ❖ Optimal viral suppression is associated with keeping clinical appointments.

According to Bartlett & Gallant (2004:58) the following is the guidance for improved adherence:

- ❖ Establish readiness prior to initiating HAART

- ❖ Address common problems: knowledge and understanding of issues, deal with adverse reactions, food issues, pill burden and dosing frequency
- ❖ Use facilitators: multidisciplinary teams (nurses, pharmacists, peers et cetera), friends, relatives, partners, and community-based organisations
- ❖ Use adherence aids: pill boxes, pictures, calendars, alarms and pagers
- ❖ Documentation: pharmacy records, questionnaire results, blood levels, partner.

As far as the researcher is concerned, IDCC does well in addressing the needs of the new patients although there is room for improvement. For example, patient education is done as well as assessing the patients' readiness to start treatment. New patients are not attended to if they do not bring a 'buddy' (*mompoti*). This system proves to be helpful as far as adherence is concerned.

Unlike at the beginning of the programme, not all patients go for counselling with the social worker during their first visit unless certain problems are identified by other personnel. They make referrals in such instances. The researcher is of the view that the current system puts more emphasis on education than on counselling. IDCC does not have adherence counsellors and relies on nurses to provide this service.

The researcher argues that, although the number of patients is increasing by the day, it is of utmost importance that patients be counselled by the social workers because they are trained in counselling and have the finesse to address psycho-social problems. Group counselling can be offered during the first visit, given that the number of patients is high, and thereafter, one-to-one counselling can be offered as the need arises. This would in no doubt call for hiring of more social workers.

Although IDCC terms the current education offered to patients, counselling, it is in actual fact health education. It is parochial in approach. It is given by the nursing personnel and it is designed in such a way that it focuses more on the clinical aspects of HIV/AIDS and the psycho-socio-economic issues that affect the patients are not addressed and this is where social workers should be brought on board.

Mhone (2002:71) endorses the above-mentioned view and notes that, the complexity of HIV spread is not to be underestimated. Many of the reasons for the failure of prevention programmes to date lie in this oversimplification, in reducing the epidemic to medical or health terms, to talk of HIV/AIDS as if socio-economic processes were merely incidental.

It is the researcher's opinion that more needs to be done in the area of counselling in addressing issues of stigma, discrimination, fear and socio-economic issues. Of great concern also is the increasing number of suicides in Botswana. These and other pertinent issues need to be explored in-depth during counselling.

The researcher observes that currently, only one social worker mans the IDCC where the current enrolment is over 7000 patients at Princess Marina Hospital. The same social worker has other responsibilities, namely, he has other wards assigned to him in the hospital. With such a high patient ratio, it is a challenge to offer effective and efficient service. The number of patients is clearly overwhelming to one person.

The researcher had the opportunity of working at IDCC when the national ARV Programme was first rolled-out in January 2002. The researcher was the only social worker counselling patients at IDCC. Even then, with the number of patients lower than it is now, the work was overwhelming.

Furthermore, the researcher alludes that patients with HIV/AIDS present with myriads of issues and counselling is a process and thus needs to be offered

even post the first visit in the form of supportive counselling. Patients need to be assisted, through counselling, through all the different stages of the disease and all their concerns addressed until they are empowered and have adopted the positive coping mechanisms to be able to face the everyday challenges in their different settings.

Taking the above-mentioned points into account, it is very clear that the IDCC managers are doing the patients a disservice by not hiring more social workers. The number of patients registered in the programme is not alone most important, but the levels of adherence as well.

MASA Antiretroviral Therapy (2004:6) confirms the above-mentioned point by stating that the bulk of work associated with implementing an ARV programme is not initiating patients on ARV therapy, but rather with maintaining the required levels of adherence and compliance.

The researcher is of the opinion that the shortage of human resource at the IDCC will have a negative impact on the success of the MASA programme, which will result in the loss in financial resources. It is important to make sure that the service that is rendered is effective and responsive to the needs of the consumers thereof, otherwise it will just be a mere exercise with negligible benefits, but expensive to the government.

The researcher notes that, with the increase in ARV sites in Botswana, the issue of adherence needs special attention given the complications that can arise as a result of non-adherence, for example, the development of resistant strains, increased sickness and deaths. With the increase in the number of patients enrolling for treatment, monitoring and evaluation tools need to be in place and utilised optimally.

Furthermore, the researcher posits that, with the opening of more ARV sites throughout Botswana, the problem of congestion will hopefully be addressed. It is clear however, from the concerns raised by the respondents that there is

a dire need for resource injection in the area of personnel, particularly doctors and pharmacists.

3.3.1.8 Ways in which respondents' quality of life changed since stopping ARVs

Majority of the respondents reported a change in the quality of their life, specifically, a general deterioration in health. The following are their responses:

'I am always anxious that I might become sick anytime.'

'I am worried that my CD4 cell count will drop.'

After stopping ARV treatment, the respondents reported that they were experiencing the following symptoms from time to time and these are the same symptoms they reported they experienced before commencing on treatment:

- ❖ Dizziness
- ❖ Bodily pains
- ❖ Generalised weakness
- ❖ Sore throat
- ❖ Mouth ulcers
- ❖ Insomnia
- ❖ Skin hyper pigmentation
- ❖ Persistent cough
- ❖ 'Yo-yo' weight and appetite.

On the other hand, few respondents reported an improvement in their health since they stopped taking ARVs and it is for this improvement that they feel there is no need for them to take ARVs. Some of these are on traditional treatment while some are not taking any treatment at all.

According to Southern African Journal of HIV Medicine (2002:4), inadequate adherence may result in partial suppression of viral replication and pressure to select viral species resistant to the administered therapy. Therapeutic efficacy is therefore reduced. Inadequate adherence is the major cause for sub-therapeutic drug levels, resistance selection and therapeutic failure. To prevent or delay resistance, long-term careful attention to adherence is therefore critical.

According to the researcher, it is clear from the responses that majority of the respondents, once they stopped ARV treatment, started experiencing the symptoms that they had prior to starting treatment. A general deterioration in health was noted from the responses given. Some of them would have done better with good social support, while some would have benefited from better follow-up and monitoring by IDCC personnel.

The researcher notes that the above-mentioned situation calls for strengthening of formal and informal forms of social support if better adherence levels are to be realised. Adherence to ARVs leads to prolonged life, improved health, reduction in hospitalisations and mortality as well as immune restoration.

3.3.1.9 Respondents' feelings when they stopped ARVs

The respondents gave different reasons as to how they felt when they stopped taking ARVs and the following are their responses:

'I feared that my health would deteriorate.'

'I experienced stigma problems. I am believing God for a job so as to join medical aid and get ARVs from a private practitioner, there is no congestion there.'

'I feared IDCC staff would be cross with me for defaulting.'

'Ke ne ke tshogile gore ke ka nna ka swa.' ('I feared that I might die.')

'I feared that my CD4 cell count would drop.'

'I started paying too much attention to any symptoms because of fear of what they could lead to.'

'I never wanted to start ARVs in the first place. I did so because I was convinced by health workers. I didn't have trouble stopping ARVs, after all, they are not a cure. I want to show people that God heals and I am going to rely on him and not on ARVs. I am not troubled by the symptoms I am having!'

'Because I was on PMTCT, I thought the effect on my health would not be that bad. I feared that ARVs would affect my unborn baby.'

'Ke dirile phoso go emisa diritibatsi.' ('I made a mistake by stopping ARVs.')

'I was worried that people will see me. There are too many people at IDCC. I was worried that people will start talking.'

Majority of the respondents reported that they were not happy to stop treatment but were forced by varying circumstances. Worry, stigma and fear remain some of the major enemies to adherence as well as ignorance about the likely consequences of stopping treatment.

It appeared some respondents either did not quite believe that they would be putting their lives at risk by stopping treatment or did not quite grasp the gravity of the risk because some of them appeared shocked at the resurgence of symptoms. With such a scenario, continued education and counselling would be of benefit to ensure the HIV/AIDS message is inculcated into the patients.

Oggins (2003:54) concurs with the above-mentioned point when he alludes that not knowing how medication works may affect adherence. For example, people accustomed to taking medication immediately after getting ill may not understand the need to take preventive medication before getting ill or for a prolonged period after getting ill (for example, year-long treatment for tuberculosis.) In a study of IV drug users in New York, most understood how tuberculosis was transmitted, but 40% did not understand the importance of adhering to TB medication. Taking combinations of medications to deal with HIV may be unfamiliar too.

In addition, Baker (2003:29) asserts that it is necessary to expose cells to ARVs, because as soon as they are discontinued, viral gene expression and replication resume. It is clear that we are yet to cure this insidious infection, because as soon as the drugs are discontinued, the virus returns in 2 to 3 weeks.

According to Goggin, Catley & Brisco (2001:87), the most commonly described negative experiences included HIV-related physical symptoms, an awareness of limited life span, alienation, and stigma.

The researcher notes that the patients who inform their families about their ARV regimens, usually get positive support as seen through the 'buddy' system at IDCC. It can be a long and lonely road if one keeps their HIV status secret for fear of stigma or discrimination. It is in this regard that counselling plays a crucial role in assisting the patient come to a point where he appreciates the importance of disclosure.

It is in this respect that the researcher lauds the Botswana ARV Programme for introducing the 'Buddy system' (*Mompoti*). This is a system whereby no patient is allowed to start ARVs without bringing along a family member or significant other who will be there to support and encourage them to take treatment as prescribed. Both patient and 'buddy' are educated on the ARV regimen to be taken by the patient.

The researcher observes that the respondents' feelings, when they stopped ARV treatment can be summed up as follows: relief, regret, heightened stress for fear of deterioration in health as well as having a sense of freedom. It should be noted however, that majority of the respondents experienced heightened stress and fear of death and resurgence of symptoms as a result of stopping ARV treatment and it is these who were willing to re-enrol in the ARV programme immediately.

3.3.1.10 Ways in which respondents feel they could have been assisted financially to enhance compliance

Majority of the respondents pointed out that they have financial problems and would appreciate government assistance in this regard, for example, being given a job or be assisted with transportation costs and food. Their responses are mentioned below.

'Because I am employed, I have no financial problems.'

'Although I am employed, my salary is not enough to sustain me, as a result, I am receiving food basket.'

'Ke tlhoka thuso ya dijo.' (*'I need assistance with food basket.'*)

'I feel government should assist me financially. I only get food basket and want to be transferred to a local hospital as this will reduce transport costs for me.'

'I am unemployed, hence I cannot afford transport cost. Although my boyfriend is employed, he does not give me money regularly. Government should assist people like me with transport money, or the local clinic transport should assist by ferrying us to IDCC.'

'I want to go to the mosque to ask for financial assistance. I wrote them once, requesting to be assisted with transport money but didn't get assistance because I didn't give them my HIV results.'

According to National Development Plan (NDP) 9 (2003-2009:24), poverty remains one of the major challenges for Botswana. The concept of poverty refers to an individual's inability to achieve minimal standards in fulfilling basic human needs such as food, clothing, shelter, health, education and sanitation services.

UNAIDS (2003:34) notes that the economic and political situation of a country affects access to HIV/AIDS-related treatment. The poorest countries have the heaviest burdens of illness and HIV/AIDS can make the existing difficulties even worse. It is much harder for people to resist infections if they do not have adequate physical and financial security, food and education. If there is an overall lack of money both nationally and individually, there are fewer funds for care and treatment.

The researcher posits that it is fundamental that government does all in its power to reduce the poverty levels, especially at the micro level. As seen from the responses, some respondent's desire to comply with treatment was thwarted by lack of financial resources.

MASA Antiretroviral Therapy (2004:1) endorses this view and notes that, "some patients are so impoverished that they simply cannot always afford to travel to the clinic when they have appointments."

In addition, Weiser, Wolfe & Bangsberg (2003:284) in their study reverberate this point and note that, "fifty percent of patients stated that their overall economic situation interfered with their ability to take treatment."

Botswana Vision 2016 (1997:9) points out that there will be a social safety net for those who find themselves in poverty for any reason. This will go hand in

hand with the provision of good quality social security, in partnership with the private sector and NGOs, aimed at vulnerable groups such as the elderly, disabled, orphans and terminally ill.

The researcher notes that programmes aimed at providing for the vulnerable groups such as the terminally ill should move hand in hand with the programmes that are being introduced, such as the ARV programme.

If a programme is introduced and the corresponding programmes are not implemented accordingly, one is likely to impede the progress or success of the other as evidenced in this study: compliance is hampered because there are not enough measures in place to tackle problems such as a patient not coming for appointments because of lack of transportation money. More needs to be done to buttress support for patients in this area.

3.3.1.11 Ways in which respondents feel family could have been supportive to assist them with compliance

Social support is defined by Hurdle (2001:73) as “the emotional support, advice, guidance, and appraisal, as well as the material aid and services that people obtain from their social relationships.”

Considerable evidence suggests that positive social support helps people maintain their health and welfare under difficult circumstances and that low levels of social support from family members were associated with higher levels of risk behaviour (Reilly & Woo, 2004:98).

According to Hurdle (2001:72), social networks and social support have been found to be beneficial to the health of individuals in a variety of ways: reducing mortality rates, improving recovery from serious illness, and increasing use of preventive health practices.

During the interviews, some of the respondents reported that their families were supportive while they were taking ARVs while others did not get any support. The following are their responses:

'My family assisted financially by buying medication for me for minor ailments and giving me transport money. They showed me love and not discrimination.'

'My husband accompanied me to IDCC sometimes.'

'My family knows my HIV status and they are supportive. I informed them I had stopped taking ARVs and they accepted my decision.'

'Two of my older siblings are also on ARVs. My family used to call me and encourage me to take my medication.'

'Whenever I visited my mother, she used to encourage me to take my medication. She also assisted me financially.'

'My family always make sure there is somebody staying with me when I become very sick. They show me compassion and support.'

It can be concluded from these responses that family support alone is not adequate to assist with adherence. Other forms of social support should be harnessed, that is, both the formal and informal forms of social support systems such as follow-up and monitoring by IDCC personnel, HIV/AIDS support groups and Faith Based Organisations.

Having social support means the patient is not carrying the burden of living with HIV/AIDS alone. Because there are significant others who know about their condition, it becomes easier for the patient to share their deepest fears and worries especially if they are ensured of confidentiality either by the health workers or loved ones. Being shown love, care and compassion is one

of the greatest things that can happen to a human being because a human being is a social being.

People living with HIV/AIDS are entitled to confidentiality in all matters to their health and HIV status. Health care workers and other professionals, such as counsellors, should encourage PLHAs to be open about their HIV status but they have no right to breach the confidentiality of any person infected or affected by HIV/AIDS (Botswana HIV/AIDS and Human Rights Charter, 2002:5-6).

According to UNAIDS (2003:31), confidentiality is about sharing sensitive information (such as a person's HIV status) only with those who really need to know. The person most affected by the information, the person living with HIV/AIDS, is the 'owner' of the information. Others must respect their wishes about sharing it. Wherever possible, the person living with HIV/AIDS should be encouraged to share the information him/herself with those who need to know. If this cannot be done, the person's consent must be obtained before passing the information to others. If people feel that their HIV status will remain confidential, they will be more likely to seek counselling, testing, treatment and support.

On the other hand, some of the respondents expressed that they wished that their family could have been supportive. Their responses are captured below:

'I wish my wife could accompany me to IDCC. My wife has relatives who are nurses and she fears to come to IDCC because she does not want them to see her.'

'I wish my family could have encouraged me to take my medication, to go for appointments and to eat healthy.'

'I wish my husband had not left work so that we could benefit from medical aid and continued to get ARVs from the private doctor because there the queues

are not long and it would not be obvious that I am taking ARV treatment unlike at IDCC where the clinic is specifically for HIV positive people.'

'If I had a literate relative nearby who would remind me of appointment dates, I would not have stopped treatment.'

'I wish my family did not squander my money. I wish there was somebody to take care of me when I am sick. Home-based care people only visit me once in a while.'

'I am denied food, transport money and toiletries at home. My family discriminates against me and discuss my HIV status with the neighbours. They say hurtful things to me. They do not want to share utensils with me.'

UNAIDS (2003:31) points out that people experience stigma when they feel ashamed or when they are made to feel ashamed about HIV/AIDS. People may also fear that others will blame them for it.

According to Reilly & Woo (2004:97), social support assumes many forms and can encompass a variety of relationships and behaviours. It can be best understood as the relationships and interactions that provide individuals with assistance or feelings of attachment. There are three types of social support: social embeddedness, that is, the connections that people have to others in their environment, perceived social support, that is, an individual's cognitive appraisal of connections to others and enacted or received support, that is, behaviours or actions performed by others as they express their support.

The researcher points out that the role of social support cannot be over-emphasised in enhancing adherence. Human beings are social beings, hence the need for the other person, be it family member or friend. It is very crucial to encourage the patient to adhere to any form of treatment, ARVs notwithstanding.

There are large numbers of people whose poor literacy severely restricts their choices in life and work. Poor literacy is strongly correlated with a greater likelihood of unemployment, lower pay when in work, poor health and less likelihood of owning a home. On the other hand, high levels of literacy are associated with higher earnings, greater participation in voluntary community activities and better health. Good literacy is a good ingredient for citizenship, community participation and a sense of belonging (Walker, Udy, Pole, May, Chamberlain & Sturrock, 2001:4).

The researcher gleans from the responses that literacy is one of the critical factors in compliance and it impacts on many programmes. The researcher posits that illiterate patients are less likely to comply with treatment as compared to their literate counterparts. They rely solely on the information they are given either at the hospital or by the media, for example. They cannot broaden their understanding by reading for themselves. This limitation could result in an insufficient grasp or appreciation of pertinent issues such as compliance.

It would be helpful if during policy formulation that such a factor was taken into consideration, for example, how the illiterate patients will be catered for in the programme in order to optimise compliance on their part. Problem specific strategies will be helpful in this regard.

3.3.1.12 Respondents' feelings about service from IDCC staff

People with HIV/AIDS require a complex array of social support services. It is critical for those working with the population to know the kinds of support that are most effective in helping people living with HIV/AIDS to sustain their health, safety and well-being (Reilly & Woo, 2004:97).

While some respondents expressed that they are satisfied with the services offered at IDCC, majority of them voiced their dissatisfaction and the main

cause for concern is the congestion at IDCC, the long queues at pharmacy and the long queues for doctors. Their responses are mentioned below:

'I am happy with the service, although at registration and pharmacy it is very slow. The staff members are friendly and welcoming. Instructions are clear. I am happy with counselling because I get answers if I ask questions.'

'The staff members are helpful. I feel patients who come from far should be assisted first so that they can get home on time.'

'Pharmacy personnel should be increased and they should work in shifts so that patients can be assisted after hours.'

'I am unhappy that the social worker turned down my request for food basket the reason being that I am employed. My salary is little.'

'There are too many patients, therefore, the clinic is always congested. The building should be extended. Because of the long queues at pharmacy, patients should be given medication enough for a year!'

'I was turned back twice because they could not find my results, I became discouraged. Nurses scold at patients.'

'Medical examination is thorough.'

'Although it is congested, I do not mind because we are called according to numbers.'

'I feel they take too long entering data on the computer.'

The researcher posits that improvements in service delivery at IDCC can go a long way in assisting with enhancing compliance. It is thus extrapolated from the responses of this study that as far as service delivery goes, IDCC would

benefit from a face-lift. This would require resource injection, especially in the recruitment of more personnel, training and re-training of current personnel and improvement and extension of IDCC building.

A study of the MASA Programme by UNAIDS (2003:61) points out that, “one of the biggest gaps identified by the study was skilled personnel to provide the treatment; everywhere, Botswana’s health services were operating with shortages of staff, and there was practically no expertise in treating HIV/AIDS. A big recruitment drive was initiated to bring on board not only extra doctors, nurses and pharmacists, but also new types of counsellors to help patients adhere to their drug regimens.”

UNAIDS (2003:61) further notes that the MASA team turned to the Harvard AIDS institute, which was already conducting clinical research in Botswana and helping the Ministry of Health to upgrade its laboratory services to co-develop a training course consisting of 12 basic lectures covering everything from immunology and virology, to drug interactions and side-effects of antiretrovirals. By mid 2003, over 700 people had completed the training course. It has become a standard training package, used also to train private practitioners and health personnel employed by the big mining houses that run their own hospitals.

The researcher is of the view that there is no doubt that the current human resource shortages at IDCC hamper service delivery. The situation is not helped by the fact that nursing personnel continue to leave for greener pastures abroad. Staff in general work under stressful conditions because they are overstretched.

Furthermore, the researcher postulates that sources of social support and perceived helpfulness differ by social group, for example, gender, ethnicity and sexual orientation. This brings into perspective the question of ethical considerations whereby it is imperative to recognise another person’s value, self-worth, uniqueness and self-identity and enhance these in every manner

possible, and acknowledge the fact that because of the universality of human beings, a blanket form of intervention will not work. Hence, intervention should be individually tailored for it to be effective and produce optimum results.

3.3.1.13 Respondents' feelings on what could have been done to assist them with compliance

Ramotlhwa (2004:6) states that, “unacceptably long queues have begun to develop at pharmacies. The solution has been to split the queue, with specific days and/or times/days reserved for those with higher CD4 counts and other times left open to the normal first come first served model.”

The need to increase personnel at the clinic was expressed by the following responses:

‘There is need to increase pharmacy personnel and doctors in order to ease congestion.’

‘There should be smaller, manageable clinics. Open more ARV sites.’

‘Nothing could have been done to assist me with compliance because I stopped treatment on my own and I knew what the outcome would be.’

‘Nothing could have been done because the decision as to whether to take ARVs or not, depends on me.’

‘I feel my medication should have been changed because I was having side-effects. IDCC building is very small. They should build another clinic or open more sites.’

‘The toilets should be far away from the reception area. It is difficult when you are trying to eat because of the smell from the toilets.’

'When coming for medication refills, we should find our package ready, so that we can just pick it and go without having to queue.'

'I was surprised to get a call from you. I thought it had something to do with 1st December, World AIDS day or to do with the changes brought by the new Health minister. Staff should be more concerned when patients do not come for appointments. They should make calls, after all, they keep our particulars.'

'Vital signs are taken in an open space at the reception. There should be a room where this is done.'

'We should be given medication that will last a year. It will ease the congestion.'

'I have seen very sick patients lying on couches. Such patients should not be kept waiting. Doctors should see them straight away.'

'Nothing can be done about the situation because people are sick.'

'I want to be transferred to my area because there is now an ARV site there. I have financial problems.'

To capture the above-mentioned point, UNAIDS (2003:30) states that in urban areas, where transport is more available and distances are shorter, people can usually get to health facilities or health workers can visit them in their homes. However, in rural areas, physical access to HIV/AIDS-related treatment is much more difficult. Some of the common physical barriers include the following:

- ❖ Health facilities may be far away, with people having to travel great distances with inadequate transport
- ❖ The terrain may be difficult to cross, for example, because of hills or rain

- ❖ There may be few vehicles or other forms of transport available.

The responses indicate that there is a need for more doctors and pharmacy personnel. Long queues at the pharmacy and for doctors is a major problem that discourages patients from utilising IDCC services, hence the stopping of treatment.

Attention should also be paid to ensuring that patients presenting with problems of antiretrovirals side-effects should be attended to as a matter of priority because side-effects, for example, vomiting, diarrhoea, skin rash, et cetera present their discomforts and inconveniences.

Another critical factor is that of privacy. While patients are consulted by the doctors in the privacy of doctors offices, the same is not done regarding checking of vital signs. This is done at the reception area in full view of all the patients who are queuing there, as noted in one of the responses. To respect the privacy of patients, such a service needs to be offered in a separate private room.

The researcher draws attention to the respondents' call for the opening of more ARV sites. The researcher therefore hopes that, because more sites are continuing to be opened, this will go a long way in improving compliance. This means, patients travel lesser distances to the clinics and reduces the problem of transport costs as well as problems of congestion.

In addition, given the responses, the researcher is of the opinion that more needs to be done in the area of education and counselling as far as stigma and discrimination issues are concerned as well as closely monitoring such patients to give them support. It should be accepted that not all patients will cope the same way. Others will need more attention than others. The problem of staff shortage poses a challenge to realising the above.

.3.1.14 Things that respondents would need in place if they were to resume ARV treatment

Majority of the respondents feel that the congestion at IDCC should be reduced as well as the long queues at pharmacy and that the current environment is not conducive for patients. Their responses are captured below:

'Staff should phone patients to confirm appointment or to check if the patient is complying with treatment. Patients who come for subsequent visits should be made aware of availability of counselling services. I ended up going for counselling at the Coping Centre for People living with HIV/AIDS (COCEPWA) because I did not know about the availability of counselling services at IDCC.'

'I need assistance with transport. I walk with difficulty. I have financial problems.'

'Staff should work in shifts so that some patients can come to the clinic after hours.'

'A vaccine should be developed so that we can come here less often. A thief grabbed my bag with ARVs inside and I was very far away from the clinic.'

'I want to be transferred to an ARV site in my area.'

'Something needs to be done about congestion and the long queues at the pharmacy.'

'I need my wife to be more supportive and accompany me to IDCC.'

'Medications should be prepared in advance for refills. IDCC should open 24 hours in order to ease congestion.'

'Hire more staff!'

'Patients who are on medical aid should go to private doctors in order to ease congestion at IDCC.'

'Home-based care should be strengthened and they should collect medication for patients who are very sick.'

'I would be encouraged to come if when coming to IDCC, I could go back home on time, not having to spend all day here.'

'If medication is causing me problems, it should be changed!'

'I do not want to start ARVs because the traditional medicine I am taking is helpful. I might consider ARVs only when I am very sick or when traditional medicine is failing.'

'Patients with a good CD4 cell count and are compliant should be given a 6 months supply of medication, then they can come to the clinic twice a year only.'

'During group counselling, patients should share how they have been helped by ARVs in order to encourage others. We should be shown educational videotapes. Educate patients on ARVs continually.'

MASA Antiretroviral Therapy (2004:1) notes that in an attempt to support doctors, pharmacists, nurses, social workers and counsellors in their task of adherence counselling, the MASA IEC team has developed a patient education leaflet focusing on adherence and related issues, such as positive living.

According to the researcher, patients need support at all levels; namely family support as well as support by health professionals. The absence of either one is likely to affect compliance. However, in the absence of family support, patients can be assisted to cope with the situation by strengthening them during counselling, for example, teaching them positive coping strategies,

encouraging them to belong to a support group and assisting them to strengthen their social support networks, be they formal or informal.

The researcher gleans from the responses given, that there is a call for ongoing counselling and education for the already existing patients in order to refresh their knowledge. Currently, at the IDCC, patients who are given intensive education are the new patients.

Some respondents stopped coming for treatment because they did not have transport money. The opening of more ARV sites will in part address this problem. For patients in remote areas, the problem still remains because the sites remain far from them.

There is also a call to buttress the Home Based Care (HBC) programme. Because of the magnitude of HIV/AIDS, HBC volunteers are faced with a mammoth task of caring for the sick at home.

It is extrapolated from the responses that HBC volunteers are barely coping with the responsibility. For those patients who do not have relatives to look after them, HBC volunteers are expected to offer assistance in this regard, for example bathing, feeding, et cetera. This could assist in enhancing compliance because for the bed-ridden patients, they collect ARVs for them. They are the patients' 'buddy' in this respect.

3.4 SUMMARY

The findings of the empirical study were analysed and interpreted in conjunction with the format of the interview schedule. The findings were also integrated with the literature findings.

While antiretroviral therapy has improved the lives of many Batswana infected with HIV, ARVs also create challenges especially with treatment adherence. To be effective, ARVs must be taken consistently and precisely and in most

cases require that the persons alter their lives significantly, for example, activities of daily living.

Fear of toxicity from the drugs and side-effects are other factors that inhibit compliance. Some patients find some of the side-effects such as vomiting, headache and nausea intolerable, hence the decision to stop antiretroviral treatment.

Furthermore, because antiretroviral treatment is taken life-long, it further compounds the problem of adherence. Some patients experience mental fatigue at the thought of having to take treatment all their lives. While some may start the treatment and respond positively to it, they develop an attitude of loyalty to the ARVs and it is reason enough to hang on to them for dear life, while others develop an exit attitude. Thus by the time the latter group actually stop taking treatment, for some, it is because they have mentally long resolved to do so.

Social support is a critical area as far as adherence is concerned. Patients with stronger social support network do better in treatment adherence compared to those who do not have it. Thus, it is crucial to strengthen the existing social support networks, as well as create new ones for optimised benefit for the patient.

Environmental factors also play a role in compliance. The current congestion and long queues at IDCC are some of the reasons why some patients no longer go for their appointments. Giving attention to such concerns can remove such barriers.

Another important factor in compliance is financial concerns. Some patients stopped going for their appointments because they did not have transport money. Others could not afford healthy food, while others had to prioritise the needs in the family, such as having to buy school uniform for their children.

Issues of stigma and discrimination greatly impede compliance and should be paid special attention to. Attention should be given to addressing them during counselling.

With the increase in suicides in Botswana, during counselling, it is important to explore if patients have suicidal ideation. Social workers have the finesse to address such problems. By so doing, many suicides can be prevented because the necessary support will be given.

Stress is a critical challenge for people living with HIV/AIDS. Patients should be encouraged to share their problems during counselling and those factors that they feel could act as fertile ground for non-compliance, for example, alcohol and drug abuse, mental illness, troubled relationships, et cetera. This will ensure that counselling intervention is tailored to address the specific needs identified.

Support services such as home-based care and social support centres continue to offer invaluable support to people living with HIV/AIDS and they should be strengthened.

HIV/AIDS education and awareness among communities is crucial because, as much as HIV/AIDS is a medical condition, it is also a social condition, and thus requires medical as well as social intervention. There is need for community engagement around ARV therapy as far as offering support is concerned. This will go a long way in curtailing problems of stigma and discrimination.

Issues of literacy are a critical challenge in realising compliance. More needs to be done to address the needs of literacy challenged patients because as is expected, levels of adherence have been found by numerous studies to be lower among them. They need more support and encouragement.

Age is another important factor to be taken into consideration when designing any programme. The needs of the elderly patient are no doubt different from those of the younger patient. They are generally slower and tend not to question much, probably owing to their limited knowledge. Poverty and illiteracy pose a challenge in realising adherence amongst the elderly.

Batswana continue to use traditional medicine for the various problems and ailments that they experience. The health authorities need to find a way to synchronise the services offered by traditional healers and those offered in the health facilities because as it appears, Batswana are not just about to stop using traditional medicine yet!

CHAPTER 4

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

In this chapter, an overview of the preceding chapters is presented. The socio-economic aspects that affect compliance with antiretroviral therapy and recommendations for intervention are described. Finally, the conclusions drawn from the literature study and empirical data are outlined as well as the recommendations for the study.

4.2 CHAPTER 1

4.2.1 SUMMARY: GENERAL ORIENTATION

In chapter 1, the following aspects were addressed: introduction, theoretical background for the study, HIV/AIDS impact, motivation for the choice of research topic, problem formulation, purpose, goal and objectives of the study, the research methodology, ethical aspects, definition of key concepts and contents of the research report.

In chapter 1 the following goal and objectives were formulated:

GOAL OF THE STUDY: To explore the socio-economic aspects that are involved in compliance with antiretroviral therapy.

The goal of the study was achieved in that an understanding of the perceptions, opinions and experiences of patients who had dropped out of the ARV programme were obtained. This was done with reference to literature study. In addition, the level of satisfaction with services rendered at IDCC was

explored, which gave some indication of the needs of patients in the ARV Programme as evidenced in chapters 2 and 3 of this research report.

OBJECTIVE 1: To provide a theoretical framework regarding HIV/AIDS, ARV treatment and compliance.

In chapter 2, the objective of gaining knowledge through in-depth literature study on compliance, HIV/AIDS, antiretroviral therapy and the socio-economic aspects was achieved, an in-depth understanding of these concepts and related dynamics was realised.

OBJECTIVE 2: To explore the socio-economic aspects that are involved in compliance with ARVs.

The objective of exploring the socio-economic aspects involved in compliance with ARV therapy was realised. Insight was obtained into the problems that affect patients on ARV treatment and the recommendations on the possible intervention strategies were given as evidenced in chapter 3 of this research report.

OBJECTIVE 3: To provide recommendations for improved service delivery to patients on ARVs in order to improve compliance.

The objective of providing recommendations for improved service delivery to patients on ARVs was achieved and integrated right through in chapters 2 and 3, but provided in-depth in chapter 4. From the study, gaps in service delivery were identified and recommendations given on the steps the managers and implementers in the ARV programme could take to address the situation.

4.3 CHAPTER 2

4.3.1 LITERATURE STUDY

In chapter 2 the following aspects were addressed: the biology of HIV/AIDS, HIV types and sub-types, antiretroviral therapy, adherence and resistance, the socio-economic aspects, HIV/AIDS prevention, the Botswana MASA ARV programme and the recommended intervention strategies.

4.3.1.1 The biology of HIV/AIDS

In this section, the biology of HIV/AIDS was covered and the related topics such as, primary infection, early HIV infection, intermediate HIV infection and AIDS were discussed.

4.3.1.2 HIV types and sub-types

The focus in this section was the classification of the HIV types and sub-types, namely HIV-1 and HIV-2 sub-types. Attention was also given to discussing CD4 cell count.

4.3.1.3 Antiretroviral Therapy

In discussing antiretroviral therapy, the following related topics were given attention: goals of therapy, indications for therapy as per the WHO guidelines of March 2004 and the clinical stages of HIV/AIDS as well as the Botswana guidelines on when to start ARV therapy.

4.3.1.4 Botswana MASA ARV Programme

The Botswana MASA ARV Programme was discussed. Attention was given to discussing aspects of service delivery, the history of the programme, the

follow-up strategies utilised in the programme as well as the challenges and lessons for the programme.

4.3.1.5 Adherence and resistance

In this section, adherence and resistance were covered. Focus was on issues such as predictors of good adherence to HIV medications as well as predictors of poor adherence to the same. Attention was also given to aspects to pay attention to in order to improve adherence.

4.3.1.6 The socio-economic aspects

The focus in this section was on the psycho-social and economic problems confronting individuals living with HIV/AIDS and their families as a result impeding compliance with antiretroviral therapy. The social barriers to adherence were also discussed.

4.3.1.7 HIV prevention and social support

In this section, HIV prevention and social support were discussed. Attention was given to issues such as confidentiality and disclosure, domestic violence and partner notification as well as the need to reinforce prevention counselling.

4.3.1.8 Intervention

Attention was given in providing intervention strategies that can be deployed in order to improve service delivery to patients on ARVs, thereby assisting with improving adherence. Intervention strategies aimed at addressing the problems that patients face were also given attention.

4.4 CHAPTER 3

4.4.1 RESEARCH FINDINGS

4.4.1.1 The time respondents got to know about their HIV status

This section covers data on when the respondents tested for HIV as well as the importance of knowing one's HIV status.

4.4.1.2 Reasons for testing

This section was concerned with identifying the factors that led to the respondents testing for HIV.

4.4.1.3 Respondents' feelings when diagnosed HIV positive

In this section, the aim was to identify the respondents' emotional reaction or response to diagnosis. Attention was also given to discussing the role of the social worker in this regard as well as the role of counselling.

4.4.1.4 Respondents' feelings when they were started with ARVs

This section was concerned with identifying the respondents' feelings and experiences, perceptions and attitudes when they were started with ARVs as well as the challenges they faced.

4.4.1.5 Ways in which ARVs improved the respondents' quality of life

The focus in this section was to find out the respondents' perceptions, views, experiences and attitudes about ARVs and to assess their quality of life while they were on ARVs.

4.4.1.6 Reasons why respondent stopped going for follow-up treatment

The aim in this section was to identify factors that contributed to respondents stopping to go for follow-up assessment and treatment at the hospital and what could be done to address such concerns.

4.4.1.7 Reasons that led to respondents not taking treatment

In this section, the focus was to find out which factors led to the respondents not taking treatment as prescribed as well as ways in which such concerns could be addressed.

4.4.1.8 Ways in which respondents' quality of life changed since stopping ARVs

This section was meant to assess the respondents' health status after stopping ARV treatment.

4.4.1.9 Respondents' feelings when they stopped ARVs

The focus of this section was to identify feelings and experiences, perceptions and attitudes of the respondents when they stopped ARV treatment.

4.4.1.10 Respondents feelings on how they could have been assisted financially

In this section, the aim was to assess the level of need for financial assistance with regard to enhancing compliance with ARVs.

4.4.1.11 Respondents' feelings on how family could have been supportive

This section was concerned with assessing the role of social support and the level of social support that the respondents were enjoying.

4.4.1.12 Respondents' feelings about service from IDCC personnel

The aim here was to identify the nature of services rendered at IDCC as well as to assess the quality of services offered, to assess customer satisfaction and the quality of public relations.

4.4.1.13 Respondents' feelings on what could have been done to assist them with compliance

This section was concerned with finding out areas for improvement as well as identifying the weaknesses and gaps in service delivery.

4.4.1.14 Things respondents would need in place if they were to resume ARV treatment

The aim of this section was to assess and identify the respondents' needs, as well as come up with ways in which these needs could be met.

4.5 CONCLUSIONS

The following conclusions are drawn from the literature study and the empirical findings:

- ❖ HIV/AIDS is a disease that affects people at all levels of social strata but appears to be concentrated more on those people in the lower social strata.

- ❖ All the respondents tested for HIV because they were forced by factors beyond their control such as appearance of symptoms or deterioration in health.
- ❖ Majority of the respondents were knowledgeable on HIV/AIDS facts.
- ❖ Social support is critical for patients on antiretroviral treatment and it should be strengthened.
- ❖ Lack of transport money featured strongly as a factor that affects compliance as well as unemployment, discrimination and stigma.
- ❖ There is a critical shortage of pharmacists and doctors as seen from this study, the shortage of which greatly impedes compliance with treatment.
- ❖ There is a need to have social workers working on a full-time basis at the IDCC so that through their counselling skills and finesse in handling the psycho-socio problems that affect patients, greater adherence levels can be realised.
- ❖ From the findings, it is clear that none of the patients were followed-up by IDCC personnel when they stopped coming for their appointments, hence they expressed the need for personnel to do this.
- ❖ Counselling services should be availed to personnel working at IDCC because, as evidenced from this study, they work under stressful conditions.
- ❖ From the responses given, it shows that the respondents did not have a full grasp of the consequences of non-adherence.
- ❖ From the findings, there is a call for on-going adherence counselling for the already existing patients.
- ❖ It is evident from the study that some respondents would not have wanted to stop treatment, were it not for the socio-economic factors affecting them, such as lack of transport money, death of a 'buddy', therefore having no one to remind them of appointment dates.
- ❖ A holistic approach is necessary in order to address the needs of patients in totality. A multi-disciplinary approach would be beneficial in this regard.

- ❖ Treatment side-effects featured as one of the hindrances to compliance. Attention should be given in addressing such concerns as a matter of priority.
- ❖ Lack of faith in ARVs as being not a cure for HIV/AIDS was noted in the responses and contributed to non-adherence.
- ❖ Proximity to the treatment centres features as a concern that affects compliance.
- ❖ Congestion at IDCC features high as a factor that impedes compliance and the respondents called for the opening of more sites, extension of the current building and having patients on medical aid go to private doctors.
- ❖ As seen in this study, an unfriendly treatment by personnel contributes to patients losing interest in utilising the services or coming for treatment.
- ❖ With regard to the issue of privacy, it was shown in this study that lack of privacy does impede compliance, for example, concerns were raised that vital signs are taken at the reception area in full view of all the patients.
- ❖ As emanates from this study, some patients, although working, have serious financial problems and called for assistance with food basket and transportation. This confirms the fact that poverty has a serious impact on the life of a person infected by HIV and impedes compliance.
- ❖ It is shown in this study that some respondents prefer traditional medicine because of the benefit they are getting, that is, they reported that their health had improved.
- ❖ As gleaned in this study, patients require counselling for the psycho-socio problems that they are faced with.
- ❖ It is evident from the literature study and empirical findings that there is shortage of staff as well as specialist skills.
- ❖ As seen in the MASA Programme, political commitment is crucial for the success of programmes.
- ❖ Patient readiness and willingness to start treatment should be assessed at all times.

- ❖ More needs to be done to take ARV treatment to people in remote areas.
- ❖ Given the 'pill fatigue syndrome' and the fact that ARVs are taken life-long, there is need for on-going adherence counselling.
- ❖ An individual's uniqueness, value and intrinsic worth, culture and belief system should be taken into consideration when rendering care.
- ❖ Majority of the respondents have faith in ARV treatment, but were however afraid to re-enrol, or did not know what to do to re-enrol.
- ❖ For majority of the respondents, their quality of life and health improved while they were taking ARVs, and deterioration was noted when they stopped treatment.
- ❖ Patient transfer to the sites nearest to them was raised as a factor that can assist with compliance.
- ❖ Unemployment comes across from this study as a barrier to adherence.
- ❖ The literacy levels for majority of the respondents were low, hence the question of in-depth grasp of issues, education and awareness messages is a concern that needs to be given careful attention. Intervention should be sensitive to the problem of low literacy.

4.6 RECOMMENDATIONS

4.6.1 RECOMMENDATIONS FROM THE EMPIRICAL STUDY

- ❖ The importance of prevention of the spread of HIV infections is irrefutable, particularly given the prevalence of the disease in Botswana. Prevention should aim at curbing the spread of the disease as well as prevent new infections. A multi-sectoral approach would be beneficial in this regard.
- ❖ The importance of social support is highlighted, both formal and informal forms of social support. These should be buttressed in order to optimise compliance.

- ❖ Regarding issues of how people treat PLHAs, there needs to be continuing education in this regard. People should be taught to be more tolerant and accepting of others who are not faced with the same plight like them.
- ❖ There is a dire need to increase personnel at IDCC, particularly doctors and pharmacists as evidenced from the study. The shortage of such personnel contributes significantly to the congestion that was reported by the respondents in this study.
- ❖ Programme or service providers should ensure on-going evaluation of the services and interventions rendered, in order to assess satisfaction, appropriateness, effectiveness and relevance.
- ❖ Given the fact that information on HIV/AIDS keeps on increasing and changing, there is a need for on-going training of the existing personnel.
- ❖ In order to reduce staff burnout and stress emanating from working with HIV/AIDS patients, there is need to engage the services of the Staff-Emotional Support Group at Princess Marina Hospital in counselling of IDCC personnel as well as the services of the social workers.
- ❖ There is a need for the development of additional services and programmes. Thus, an in-depth needs assessment based on the identified needs of patients and their families or caregivers is called for.
- ❖ Society should be educated on compliance; the importance of compliance and the dangers involved in non-compliance so that the level of support for those on ARVs can be heightened at family or household level.
- ❖ A holistic approach is needed in order to attend to and address in totality the needs of the patients and the myriads of problems that patients have regarding compliance.
- ❖ Age and literacy are some of the critical factors that should be taken into consideration when designing programmes and policy.

4.6.2 RECOMMENDATIONS FOR THE SOCIAL WORK PROFESSION

- ❖ There is a need to have social workers based at the IDCC on a full-time basis so that they can assess and intervene in cases of patients presenting with various psycho-social and economic problems.
- ❖ Areas of social work expertise, such as counselling with individuals and families, as well as group work (lifeskills and therapeutic) and community work, (resource linking and advocacy) should be tapped in order to enhance compliance. The social worker's training and finesse in dealing with psycho-social problems puts them in a better position to handle such issues.
- ❖ Social workers need to define their role more clearly, particularly within a multidisciplinary setting where role blurring and professional territoriality occur. They should take their rightful place and play their rightful role in the multidisciplinary team.
- ❖ Social workers should strive to uplift the image of the profession and to demonstrate their passion for excellence in service delivery.

4.6.3 RECOMMENDATION FOR FURTHER RESEARCH

This research study focussed only on the socio-economic aspects that are involved in compliance with antiretroviral therapy and focus was on the patients. Hypothesis and assumptions for further research studies could include:

- ❖ If the perceptions and opinions, experiences and attitudes of caregivers regarding antiretroviral therapy are known, an improvement in service-delivery and compliance could occur.
- ❖ If the cultural factors that are involved in living with HIV/AIDS are understood, intervention strategies can be specifically tailored.
- ❖ If service providers or programme managers could evaluate existing services and programmes, insight into the needs and perceptions of

those utilising these services and programmes may be known, resulting in improved service delivery.

- ❖ If the monitoring and evaluation tools can be fully utilised, greater adherence levels can be realised.
- ❖ In this study, a lack of information on patients who were no longer taking ARV treatment was experienced. Further research in this regard is recommended.

BIBLIOGRAPHY

- ACHAP. 2003. *Challenges and Learnings of ARV Implementation in Botswana*. Gaborone: Government Printers.
- Andrews, S. 2002. *Adherence to ARV regimens*. The Southern African Journal of HIV Medicine. South Africa.
- Arno, P. S. & Green, J. *The Economics of AIDS*. 1990. Massachusetts: The Medical Publishing Group.
- Babbie, E. 1992. *The Practice of Social Research*. 6th ed. Belmont: Wadsworth Publishing Company.
- 1998. *The practice of social research*. 8th ed. Belmont: Wadsworth Publishing Company.
- 2004. *The Practice of Social Research*. 10th ed. Belmont: Wadsworth Publishing Company.
- Babbie, E. & Mouton. 1998. *The Practice of Social Research*. Belmont: Wadsworth Publishing Company.
- Baker, A. C. 1994. *New Paradigms in HIV Therapy: Boosting Immunity*.
- Barker, R. 2003. *The Social Work Dictionary*. 5th ed. Washington DC. NASW Press.
- Bartlett, J. G. & Gallant, J. E. 2004. *Medical Management of HIV Infection*. USA: Johns Hopkins Medicine.
- Bless, C. & Higson-Smith, C. 1995. *Fundamentals of Social Research Methods- An African Perspective*. 2nd ed. Lusaka: Juta & Co.

Botswana Guidelines on Anti-Retroviral Therapy. 2002. Gaborone: Ministry of Health.

Botswana HIV/AIDS and Human Rights Charter. 2002. Gaborone: The Botswana Centre for Human Rights & Botswana Red Cross Society.

Botswana Vision 2016. 1997. *Towards Prosperity for all.* Gaborone: NACA.

Botswana National Policy on HIV/AIDS. 1998. Gaborone: Ministry of Health.

Botswana National Strategies Framework for HIV/AIDS. 2003-2009. Gaborone: Pyramid Publishing.

Botswana Population and Housing census. 2001. Gaborone: Government Printing.

Botswana Second Generation HIV/AIDS Surveillance. 2002. Gaborone.

Botswana Second Generation HIV/AIDS surveillance. 2003. Gaborone.

Cohen, P. T., Sande, M. A. & Volberging, P. A. 1990. *The Economics of AIDS.* Massachusetts: The Medical Publishing Group.

Darkoh, E. 2003. In MASA Antiretroviral Newsletter. 2003. *Workstreams, Learnings and Challenges Associated with Launching Botswana National ARV Programme.* Gaborone.

–2004. In MASA Antiretroviral Newsletter. 2004. *Remarkable Adherence Levels Still not Good Enough.* Gaborone.

De vos, A. S. 2002. Qualitative Data Analysis and Interpretation. In De vos, A. S., Strydom, H., Fouche, C.B. & Delport, C. S. L. 2002. *Research at*

Grassroots For the Social Science and Human service Professions. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

De vos, A.S., Strydom, H., Fouche, C.B. & Delpport, C.S.L. 2002. *Research at grassroots: For the social science and human service professions*. 2nd ed. Pretoria: J.L. Van Schaik Publishers.

Dooley, D. 1990. *Social Research Methods*. 2nd ed. New Jersey: Prentice Hall.

Doweiko, J. 2001. *HIV 1 Virology and Immunology*.

Essex, M. 2001. *HIV Replication, Mutation and Drug Resistance*.

Fouche, C. B. & Delpport, C. S. L. 2002. Introduction to the Research process. In De vos, A. S., Strydom, H., Fouche, C. B. & Delpport, C. S. L. 2002. *Research at Grassroots For the Social Science and Human professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Friedland, G. 2004. *Adherence to HAART*. The Southern African Journal of HIV Medicine. South Africa.

Future Positive. 2004. *MASA: Balancing Risk Against Roll-out*. Gaborone: Acardia Communications.

Goggin, K., Catley, D., Brisco. S.T., Engleson, E. S., Rabkin, J. G. & Kottler, D. P. 2001. A Female Perspective on Living with HIV Disease. *Health and Social Work*. 26(2):87.

Government of Botswana Country Report on HIV/AIDS. 2002. Gaborone: NACA.

Greef, M. 2002. Information Collection: Interviewing. In De vos, A. S., Strydom, H., Fouche, C.B. & Delpport, C.S. L. 2002. *Research at grassroots For the Social Science and Human service Professions*. 2nd ed. Pretoria: J.L. Van Schaik Publishers.

Hornby Oxford Advanced Learner's Dictionary. 2000. New York: Oxford University Press.

Hurdle, D. E. 2001. *Social Support: A Critical Factor in Women's Health and Promotion*. 26(2):87.

Kaiser, H. J. 2002. *Guidelines for the Use of Antiretroviral Agents in HIV Infected Adults and Adolescents*.

Lachman, S. J. 2000. *Heterosexual HIV/AIDS as a global problem*. Pietermaritzburg: J.B. Israelson.

Lachman, S. L. 1995. *Heterosexual HIV/AIDS as a Global Problem*. Bramfontein: TPS Drug Information Centre.

Lee, S.M. 1997. *Asperger's disorder as experienced by siblings*. Unpublished M.A [Psychology] dissertation. University of Pretoria.

Libman, H & Witzburg, R.A. 1996. *HIV Infection*. 3rd ed. Boston: Little Brown & Company.

Linsk, N. L., Mitchell, C. G., Despotes, J., Cook, J., Razzano, L., Grey, D., & Wolf, M. 2002. *Evaluating HIV Mental Health Training: Changes in Practice and Knowledge for Social Workers and Case Managers*. 27(1):67.

Management and Development Publication. 2003. *Challenges and Learnings of ARV Implementation in Botswana*. Gaborone: Government Printers.

- MASA Antiretroviral Therapy Newsletter. 2003. *Site Update*. Gaborone.
_2004. *Looks are Deceiving*. Gaborone.
–2004. *Patient Enrolment Update*. Gaborone.
–2004. *Impact of ARV Therapy on the Health System*. Gaborone.
- Mazonde, P. MASA's New Dawn Taking Time. *In Future Positive*. 2004. Gaborone: Arcadia Communications.
- Mhone, G. C. Z. 2002. *The Economic Impact of HIV/AIDS in Africa*. In USAID, 2002. *Economics and Governance in South Africa: Key Issues in Understanding Response*. Johannesburg.
- Mouton, J. 2001. *How to Succeed in Your Master's and Doctoral Studies*. Pretoria: Van Schaik.
- National Development Plan 9*. 2003/2004. Gaborone: Government Printers.
- Neuman, W.L. 1997. *Social research methods*. 3rd ed. London: Allyn & Bacon.
-2000. *Social Research Methods*. 4th ed. London: Allyn & Bacon.
- New King James Version Bible. 1985. *Matthew 7:3*. Nashville: Thomas Nelson Publishers.
- Oggins, J. 2003. Notions of HIV and Medication Among Multiethnic People Living with HIV. *Health and Social Work*. 28(1): 54.
- Orrell, C. 2003. *The Art of HAART: A Practical Approach to ARV Therapy*. 21[6], May: 308.
- O'Sullivan, E., Rassel, G. R. & Berner, M. 2003. *Research Methods for Public Administrators*. 4th ed. New York: Addison Wesley Longman.

Oxford Advanced Learner's Dictionary. 1989. New York: Oxford University Press.

Patton, M.Q. 2002. *Qualitative Research and Evaluation Methods*. 3rd ed. London: Sage Publications.

Ramotlhwa, S. L. 2004. Challenges and Insights from Botswana's National Antiretroviral Programme. In *MASA Antiretroviral Therapy*. Gaborone.

Reilly, T. & Woo, G. 2004. *Social Support and Maintenance of Safer Sex Practices Among People Living with HIV/AIDS*. 29(2): 98.

Ritchie, J. & Lewis, J. 2003. *Qualitative Research Practice*. London: Sage Publications.

Southern African Journal of HIV Medicine. 2002. *Adherence to Antiretroviral Regimen*. South Africa.

– 2002. *Antiretroviral Therapy in Adults*. South Africa.

–2000. *Guidelines for ARV Therapy in Adults*. South Africa.

Strydom, H. 2002. Ethical Aspects of Research in the Social Science Professions. In De vos, A.S., Strydom, H., Fouche, C. B. & Delpont, C. S. L. 2002. *Research at Grassroots For the Social Science and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. 2002. Sampling and Sampling Methods. In De vos, A. S., Strydom, H., Fouche, C. B. & Delpont, C. S. L. 2002. *Research at Grassroots For the Human Science and Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. & Delpont, C. S. L. 2002. Sampling and Pilot Study in Qualitative Research. In De vos, A.S., Strydom, H., Fouche, C. B. & Delpont, C. S. L. 2002. *Research at Grassroots for the Human Science and Service Professions*. 2nd Edition. Pretoria: J. L. Van Schaik Publishers.

Thomas, D. *Oxford Advanced Learner's Dictionary*.1997. New York: Oxford University Press.

UNAIDS. 2003. *Accelerating Action Against AIDS in Africa*. Geneva –2003. *Handbook on Access to HIV/AIDS Related Treatment*. Geneva.

ASAID. 2002. *The Macroeconomic Impact of HIV/AIDS in South Africa*. Geneva

Van der Ven, A. 2002. *Essentials for Antiretroviral Therapy in Botswana*. Botswana.

Walker, M., Udy, K., Pole, J., May, S., Chamberlain, G. & Sturrock, F. 2001. *Adult Literacy: An Urgent Priority*. Newzealand: Ministry of Education.

Webb, D. 1997. *HIV/AIDS in Africa*. London: Pluto Press.

Weiser, S., Wolfe, W., & Bangsberg, D. 2003. *Barriers to ARV Adherence in Botswana*. 34(34):284.

Whiteside & Sunter. 2002. *The Economic Impact of HIV/AIDS in Africa*. USAID. Geneva.