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**Strengthening the Capacity of Caregivers of Children on
Antiretroviral Therapy in Mahalapye, Botswana**

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A minor dissertation submitted in partial fulfillment of the requirements for the
award of the degree of MPHIL in Public Policy

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Compulsory Declaration

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to and quotation in this dissertation from the work or works of other people has been attributed and has been cited and referenced.

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Date: 4/02/2010

Signed by candidate

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ABSTRACT

The availability of free ARV therapy in the public health sector has brought hope to people living with HIV/AIDS in Botswana. However, provision of ARV therapy presents challenges to the health sector and individuals who access them. ARV therapy is a lifelong commitment that requires from the health service an uninterrupted supply of drugs, close monitoring, the administration of complicated drug regimens and managing complications. The success of treatment depends on the ability of the patient to take drugs as prescribed and the caregiver of a child who is on ARV therapy plays a crucial role in this process. It was against this background that this study investigated the lived experiences of caregivers and the implications of their experiences for ARV policy. The study explored challenges in the care process and the coping strategies devised to address them. It also elicited suggestions on what could be done to create a supportive environment for provision of care. The argument of this thesis is that for ARV policy to be successful, it should not only focus on challenges within the health system but should also address problems faced by the caregivers. These challenges have a potential to undermine the success of the policy.

The study was conducted in Mahalapye Hospital in Botswana, which started providing ARV therapy in 2003. The study used a combination of qualitative and quantitative research methods. A purposive sampling of nine caregivers who varied by age, sex and area of residence participated in in-depth interviews. Forty-nine caregivers completed the questionnaire that was used to collect socio-demographic data.

The results showed that most of the caregivers were biological parents, who were living with HIV/AIDS and as such grappling with their own health problems. It was evident that caring, which was predominantly done by women, was performed under difficult conditions of poverty. High levels of income poverty were observed and this was attributed to unemployment. Food security was an overwhelming challenge faced by caregivers. Transport costs to access treatment were a major challenge and were cited as the main reason why patients miss appointments and end up defaulting from treatment. There was an overwhelming need for financial support to buy food, cater for transport to the treatment centre and buy other household needs.

Table of Contents

ACKNOWLEDGEMENTS	I
ABSTRACT	II
TABLE OF CONTENTS	III
LIST OF FIGURES	V
LIST OF TABLES	V
LIST OF APPENDICES	V
CHAPTER 1	1
INTRODUCTION	1
OBJECTIVES OF STUDY	4
STRUCTURE OF THE DISSERTATION	5
CHAPTER 2	7
BACKGROUND OF BOTSWANA	7
HEALTH CARE SYSTEM	9
OVERVIEW OF THE HIV/AIDS EPIDEMIC IN BOTSWANA.....	11
CHAPTER 3	14
LITERATURE REVIEW	14
POVERTY AND HIV/AIDS	14
TREATMENT RELATED COSTS	16
DISCLOSURE OF THE CHILD'S HIV STATUS	17
HIV/AIDS STIGMA AND CARE GIVING	17
DRUG RELATED ISSUES	19
THE BURDEN OF CARE	19
SUPPORT SYSTEM.....	20
CHAPTER 4	24
THE POLICY PROCESS: THEORETICAL FRAMEWORKS	24
TYPES OF POLICIES.....	25
ACTORS IN THE POLICY PROCESS	28
MANAGING POLICY IMPLEMENTATION	30
AN OVERVIEW OF THE HISTORY OF HIV/AIDS POLICY IN BOTSWANA	30
NATIONAL HIV/AIDS TREATMENT GUIDELINES	32
CHAPTER 5	34
THE STUDY	34
STUDY SETTING	34

STUDY POPULATION.....	35
SAMPLING	35
RESEARCH DESIGN.....	36
<i>Qualitative Research Design</i>	37
<i>Quantitative Research Design</i>	38
PILOT STUDY.....	38
DATA COLLECTION	39
DATA COLLECTION PROCESS	40
QUANTITATIVE DATA ANALYSIS	40
QUALITATIVE DATA ANALYSIS.....	41
ETHICAL CONSIDERATIONS	41
<i>Autonomy</i>	42
<i>Anonymity</i>	42
<i>Non-Maleficance</i>	42
<i>Justice</i>	43
CONCLUSION.....	43
CHAPTER 6.....	44
STUDY FINDINGS	44
PROFILE OF PRIMARY CAREGIVERS.....	47
<i>Respondent 1: "James"</i>	47
<i>Respondent 2 "Mumpsy"</i>	49
<i>Respondent 3 "Thato"</i>	50
<i>Respondent 4: "Keletso"</i>	51
<i>Respondent 5: "Kitso"</i>	51
EMERGING THEMES FROM PRIMARY CAREGIVERS	52
<i>Theme 1: Monitoring the Child's Treatment</i>	52
<i>Theme 2: Health of the Child</i>	54
<i>Theme 3: Disclosure of Child's HIV Status</i>	55
<i>Theme 4: Financial Constraints / Poverty</i>	57
<i>Theme 5: Social and Psychological Support</i>	60
<i>Theme 6: Stigma and Discrimination</i>	62
<i>Theme 7: Health of Other Household Members</i>	63
EMERGING THEMES FROM SECONDARY CAREGIVERS	64
<i>Theme 1: Adherence Problems</i>	64
<i>Theme 2: Poverty</i>	67
<i>Theme 3: Non-Disclosure to the Child</i>	68
<i>Theme 4: Lack of Psychological Support for Health Workers</i>	69
CONCLUSION.....	70
CHAPTER 7.....	73
DISCUSSION.....	73

CHAPTER 8.....	80
CONCLUSION AND POLICY RECOMMENDATIONS	80
SUMMARY OF FINDINGS	80
RECOMMENDATIONS	82
<i>Decentralize ARV Programme</i>	82
<i>Introduce Quarterly Visits</i>	82
<i>Poverty Alleviation</i>	83
<i>Strengthening Psycho - Social Support</i>	84
<i>Policy</i>	85
REFERENCES.....	86

List of Figures

FIGURE 1: BOTSWANA MAP	8
FIGURE 2: HIV/AIDS PREVALENCE 2002-2006	12
FIGURE 3 HIV PREVALENCE BY AGE GROUPS	13

List of Tables

TABLE 1: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS AT MAHALAPYE HOSPITAL	44
TABLE 2: EMPLOYMENT STATUS AND GENDER OF THE CAREGIVER	45
TABLE 3: AGE AND GENDER OF THE CAREGIVER	45
TABLE 4: HOUSEHOLD INCOME AND RELATION TO CHILD	46

List of Appendices

APPENDIX 1: CONSENT FORM	93
APPENDIX 2: SEMI-STRUCTURED INTERVIEW GUIDE	95
APPENDIX 3: QUESTIONNAIRE FOR PRIMARY CAREGIVERS.....	96
APPENDIX 4: INTERVIEW GUIDE FOR SECONDARY CAREGIVERS.....	98

CHAPTER 1

INTRODUCTION

Botswana has one of the highest HIV prevalence rates in the world. The prevalence is currently over 30% amongst pregnant women attending government antenatal care clinics (National AIDS Coordinating Agency, 2006). The first case of AIDS was reported in 1985 and since then the country has witnessed the epidemic unfold at an alarming speed and on a scale causing “untold misery and suffering” (United Nations Development Programme, 2000: 1). The impact of the epidemic has been characterized by prolonged illness, death, especially of young adults, and a growing orphan population (National AIDS Coordinating Agency, 2006). By the end of 2006, the Joint United Nations programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) estimated that there were 270,000 people living with HIV in Botswana, whose total population is 1.7 million; almost 16% of the total population. The report further indicated that there were 120,000 orphans in the country because of HIV/AIDS (UNAIDS, 2006b). Because of its devastating social, economic and human effect, HIV/AIDS is a major public policy issue in Botswana.

The advent of antiretroviral (ARV) drugs in developed countries in the 1990's significantly improved the quality of life of people living with HIV/AIDS but remained out of reach for developing countries. Even though ARV therapy is not a cure for HIV/AIDS, it is able to reduce viral load to undetectable levels and thus lower the incidence of opportunistic infection, infectiousness of the disease and mortality (Idoko et al., 2006). The advent of ARV therapy has transformed HIV/AIDS into a manageable chronic disease. Despite the fact that ARV therapy can improve the quality of life of people living with HIV/AIDS, access to treatment is poor in developing countries. Idoko, et al., (2006:386) assert that by 2005 only "5% of the six million people who require ARV's in resource constrained countries" were actually accessing the life saving drugs. However, in southern Africa this picture has improved substantially since then. The reductions in the price of drugs and the global advocacy to accelerate treatment in developing countries has helped to improve accessibility of ARV treatment in resource limited nations (Ruxin, et al., 2005). The ability of developing nations to scale up ARV therapy has been supported by a number of international initiatives such as Global Fund to fight HIV/AIDS, Tuberculosis and Malaria, The United State's

President's Emergency Plan for AIDS Relief (PEPFAR), the Clinton Foundation and the Bill and Melinda Gates Foundation (Poku, 2005; Idoko, et al., 2006) ,

The government of Botswana took a policy decision in 2000 to provide ARV therapy through the public health sector for people living with HIV/AIDS. This decision was guided by the magnitude of human suffering and the devastating impact of the epidemic. Antiretroviral therapy has been provided through the public health sector since 2002 and treatment for children living with HIV has been integrated into treatment sites for adults (Ministry of Health, 2003).

The 2007 UNICEF report on children and AIDS indicated that many countries have been able to expand treatment for children by integrating it into the adult treatment sites. However, the report showed that only 10% of children who needed treatment were actually getting it. Because most children who are living with HIV/AIDS do not have access to ARV drugs they have very high rates of morbidity and mortality; up to 75% within the first five years of life (UNICEF, 2007). With access to good health care such as treatment of opportunistic infections and the availability of ARV therapy, the survival rate of many children living with HIV has improved. The 2007 UNICEF report further indicated that in 2005, eighty four per cent of children who needed treatment were receiving it in Botswana.

It is worth noting that ARV therapy is a complex and demanding process for the client and the caregiver and this is even more challenging if it involves a child. In order to sustain viral suppression the client should maintain an adherence rate of 95% and above. Simply stated, 95 of every 100 pills must be taken correctly at the stipulated time. This requires a strong commitment on the part of the caregiver to maintain high levels of adherence (Tindyebwa, et al., 2004). Those on treatment are expected to take their medications on a regular basis for the rest of their lives. They have to make frequent and regular visits to the treatment site so that treatment progress can be assessed and so that any adjustment, if needed, can be made (Poku, 2005). For a child who is on treatment, carrying out these activities depends on the dedication of the caregiver who in most cases has multiple responsibilities. Since the success of ARV, therapy depends on the ability of the patient to take treatment as prescribed the caregiver of a child who is on treatment plays a crucial role (de Korte et al., 2004; Tindyebwa et al., 2004).

Despite the role-played by caregivers in making children's treatment possible the literature tends to focus on people receiving treatment. There is little emphasis directed to caregivers

themselves. As a result, there is limited information concerning the experiences of caregivers of children who are on ARV therapy. Yet caring for HIV positive children places enormous demands on families and households and particularly on the caregivers themselves. To enable caregivers to cope with the demands of looking after an HIV positive child it is crucial to hear their voices so that their support needs can be identified and addressed. It is therefore important to explore the lived experiences of caregivers, identify their needs and the difficulties that they face in their care giving roles and understand the coping strategies they employ. The need to focus on caregivers was proposed by Ogden, et al., 2006 who state that "making the carer visible and bringing her into focus of national and international HIV/AIDS policies will enable these policies to provide a truly holistic continuum of care for those living with HIV/AIDS, their families and community." Ogden et al., (2006) also argue that caregivers should be assisted to cope with the demands of care giving. They content that even though ARV therapy has improved lives some people have had difficulties in accessing services while others may end up dropping out of treatment, which, as indicated above, affects the effectiveness of treatment.

The need to focus on caregivers has also been advanced by Orner (2006) who investigated the impact of care giving at household level. She (Orner 2006:236) argues that it is "important to identify challenges faced by caregivers at household level in order to inform care policies". The research concluded that care giving was constrained by lack of resources, poverty and stigma.

The 2004 UNICEF framework for the protection, care and support of orphans and vulnerable children also emphasised the need to help families cope with the demands of caring for children affected by HIV/AIDS. It places considerable emphasis on strengthening the capacity of households to be able to survive the challenges imposed by HIV/AIDS. This calls for government, civil society and the community to put in place support mechanisms to assist households taking care of children affected and infected by HIV.

This study supports these proposals. It argues that if ARV policy is to be successful it should consider not only the challenges within the health system related to the delivery of treatment, but it should also consider the problems faced by caregivers. In this, it is suggesting that the scope of health policy should be extended to include consideration of its impact on the intended clients.

The thesis explores these challenges in the context of the rural district of Mahalapye, Botswana where ARVs are available to adults and children alike through the public health system. Based on questionnaires and in-depth interviews with caregivers of children on ARV therapy, it aimed at understanding the challenges they experience. In particular, it explored their views on the financial implications of care giving, disclosure of the child's HIV positive status and the kind of support they receive from family members, the community and the state. It also explored the issue of stigma that may affect the care-giving role. The interviewees were also asked what they felt should be done to help them cope with the demands of care giving. The issues investigated were identified in the literature as the most pressing concerns of caregivers.

Objectives of Study

- To describe the socio-demographic characteristics of primary caregivers. A demographic profile was included to determine who the caregivers are and the resources available to them for caring.
- To explore and describe the experiences of caregivers of children who are on ARV therapy in regard to administering medications, financing food, hospital visits and other services, and dealing with the issues of disclosure of HIV status and stigma.
- To identify the challenges and the needs of caregivers of children who are on ARV therapy.
- To identify the nature of support caregivers receive from family members and the community such as support groups, churches, NGOs and government institutions.

The sustained ability of caregivers to support children on ARV therapy is a significant facilitator or barrier to treatment for children. Therefore, this study hopes to contribute to a better understanding of the challenges linked to care giving roles that may affect the effectiveness and the quality of care provided. The findings of the study will be useful to those planning and/or managing support services to caregivers of children who are on ARV therapy. It should enable them to strengthen the capacity of these services. The study also lays a methodological foundation for further research in other geographical areas and social contexts, which may be different from Mahalapye.

Structure of the Dissertation

The study is divided into eight chapters.

Chapter 2 discusses the background of Botswana where the study was conducted. It gives an overview of the HIV/AIDS epidemic in Botswana and the organization of the health care system in the country.

Chapter 3 discusses literature reviewed in relation to HIV/AIDS and care giving. Literature reviewed focuses on the following sub-topics: HIV/AIDS and poverty, treatment related costs, disclosure of the child's HIV status, stigma and care giving, drug related issues, the burden of care and support systems.

Chapter 4 discusses the theoretical framework of policy process and policy response to the epidemic in Botswana. This section discusses key policy documents; HIV/AIDS Policy, strategic plans and HIV/AIDS Treatment Guidelines. It is argued that the national HIV/AIDS policy places considerable demands on caregivers and that the challenges facing them should be incorporated in policy formulation.

Chapter 5 describes the research methodology used in this study to explore the experiences of caregivers. The study used both quantitative and qualitative methods to collect data. This chapter also elaborates on the ethical issues of conducting the study.

Chapter 6 presents the findings of the study. This chapter discusses the challenges facing caregivers of children on ARV therapy in Mahalapye. The demographic characteristics of caregivers and the themes emerging from interviews are discussed.

Following the presentation of findings, Chapter 7 discusses the findings in relation to other published research.

Chapter 8 concludes the dissertation and argues that households with children affected by HIV/AIDS are experiencing a deterioration of their socio- economic status. It proposes that they should be assisted to cope with the demands of care giving. The chapter also discusses possible policy initiatives that could be used to strengthen the capacity of caregivers.

Definition of Terms

Primary Care Giver

For the purposes of this study, a primary caregiver refers to a person who lives with the child who is on ARV therapy and is involved in the daily care of the child, such as supervision of treatment, accompanying child for medical appointments. The caregiver is usually a biological parent or a relative.

Secondary Care Giver

For the purposes of this study, a secondary caregiver refers to a person who provides care and support but does not live with the child. For this study secondary caregivers were defined as nurses, social workers and counsellors at the treatment sites.

Child

For the purposes of this study, a child refers to anybody who is under the age of 15 years and is on ARV therapy.

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CHAPTER 2

BACKGROUND OF BOTSWANA

Botswana is a landlocked country in southern Africa covering an area of 582,000 square kilometres with a population of 1,680,863 people. About 84% of Botswana is covered by the Kalahari Desert. Botswana borders on Namibia, South Africa, Zimbabwe, and Zambia (Figure 1). Botswana has two official languages, Setswana and English (Republic of Botswana, 2003a; Lindsay, et al., 2003).

Eighty eight per cent of the population of Botswana is concentrated in the south eastern parts of the country. This area has good soil and a climate which is favourable for arable farming. The western part of the country which is desert is sparsely populated (Republic of Botswana, 2003).

The 2001 census reported an increase in mortality, which had negatively affected average life expectancy. This had fallen to 55.6 years from 65.3 years in 1991. The census also recorded a decline in the population of children under the age of 15 years from 43.2% in 1991 to 36.6%. This decline was attributed to a decrease in fertility rate and the high mortality of infants and children less than five years caused by AIDS (Republic of Botswana, 2001; Republic of Botswana, 2003a).

The National Development Plan 9 (2003- 2009) indicates that in the year 2000 the enrolment for primary school education was 92% and that there was 100% transition rate from primary education to junior secondary education. This has ensured that all Botswana children have ten years basic education. This is attributable to the government policy of free education.

Figure 1: Botswana Map



Botswana was one of the poorest countries in the world at independence in 1966, but is now classified as a middle-income country. Despite this classification, poverty is still one of the major challenges facing the country. According to Lindsay et al, (2003) 47 percent of the population live below the poverty datum line of US\$1.00 per day. Poverty is concentrated in the rural areas especially Kgalagadi and Ghanzi districts where most people depend on social welfare. Like most developing countries, poverty in Botswana has a gender bias; female-headed households are the most vulnerable. Because of the high levels of poverty, many households have difficulties in meeting their basic needs such as food, clothing and shelter (UNDP, 2000; Lindsay, et al, 2003; Republic of Botswana, 2003a; Siphambe, 2003).

Health Care System

The delivery of health care in Botswana is a shared responsibility between the Ministry of Health (MOH) and Ministry of Local Government (MLG). The MOH has overall responsibility for policy direction and is responsible for hospital services. The MLG is responsible for the provision of primary health care services through Town and District Councils. Based on the primary health care approach that emphasizes the accessibility and affordability of services, the country is divided into 24 decentralized health districts (Republic of Botswana, 2000; Owolabi and Shaibu, 2002; Republic of Botswana, 2003a).

The lowest level of the health care system is the mobile stop (outreach services) which is normally in remote areas where access to health facilities is difficult. Mobile stops do not have fixed structures but are offered from a vehicle equipped for the purpose staffed by health teams from the nearest health facility. The health post is the second lowest level and is found in villages that have a population of 500-1000 people. Health posts are staffed by nurses and Family Welfare Educators. Health posts offer limited primary health care services such as family planning, immunizations, antenatal care and treatment of common diseases (Republic of Botswana 2000; Owolabi and Shaibu, 2002).

A clinic with or without maternity facilities is found in places which have a population of 5000 to 10 000 people. Clinics are mostly staffed by nurses, midwives and Family Welfare Educators. Clinics provide curative and preventive health services. Patients at clinics and health posts are mostly attended by nurses and at times by visiting medical officers. Patients with acute illnesses that cannot be managed at the lower levels are referred to the hospitals.

Primary hospitals offer general health care services including laboratory and x-ray services. A primary hospital has a bed capacity of 20-70 beds and it is staffed by medical officers, nurses, laboratory technicians and pharmacy technicians. Currently there are 17 primary hospitals in the country (Republic of Botswana, 2000).

District hospitals have a bed capacity of 70-400 and they are found in major villages and towns. A district hospital offers general health care services but on a larger scale than a primary hospital. District hospitals receive specialist support from referral hospitals. Currently, there are 12 district hospitals of which three are mission hospitals and three are hospitals operated by the diamond and copper mines. The referral hospitals are at the apex of the health care system and they offer specialist health care. The two-referral hospitals are

located in the south (Gaborone) and north (Francistown) of the country. There is one psychiatric hospital and one private hospital. Referral hospitals have a bed capacity of 400 and above (Republic of Botswana, 2000; Owolabi and Shaibu, 2002).

The primary health care approach has improved accessibility of health care services to people in the countryside but there are still challenges facing the system. The shortage of skilled health personnel is a major constraint and it affects the capacity of the system to meet the health needs of the population. Botswana, like other African countries, had a limited capacity to meet the health needs of the people even before HIV/AIDS. This situation has been complicated by the emergence of HIV/AIDS, which has a high disease burden. The shortage of skilled health workers in the country has been exacerbated by the migration of health professionals to the developed countries and the fact that the country does not have a medical school to train its own personnel. The shortage of qualified health personnel makes the provision of ARV therapy a challenge especially in the rural areas where the problems are more pronounced (Republic of Botswana, 2000; Poku, 2005).

Before ARV therapy was introduced, the Ministry of Health conducted an assessment to determine the feasibility of providing it in the public health sector. The assessment focused on the internal process such as staffing, financial requirements, infrastructure and modalities of delivery. The results of the assessment showed that there was need for significant additional resources to improve the capacity of the system. The assessment recommended that the number of pharmacists should be increased by 179%, Laboratory Technicians by 115%, Doctors by 29% and nurses by eight per cent. The assessment further showed that the capacity of the system to do Elisa tests needed to be increased by 48%; CD4 tests by 2500% and that storage facilities for medicines and other supplies needed to be increased by 420% (de Korte, Mazonde, and Darkoh, 2004). These figures eloquently demonstrate that the health care system was ill-equipped to deliver ARV treatment to the population at that time.

Access to appropriate care and treatment is also affected by the structure of the health system and the inequalities that exist between the urban and rural areas. The lower levels of the health care system (clinics and health posts) are under-resourced in terms of personnel, physical infrastructure, equipment and supplies. Compared to hospitals, the lower levels have limited capacity to address a range of ailments including HIV/AIDS. This level is mostly

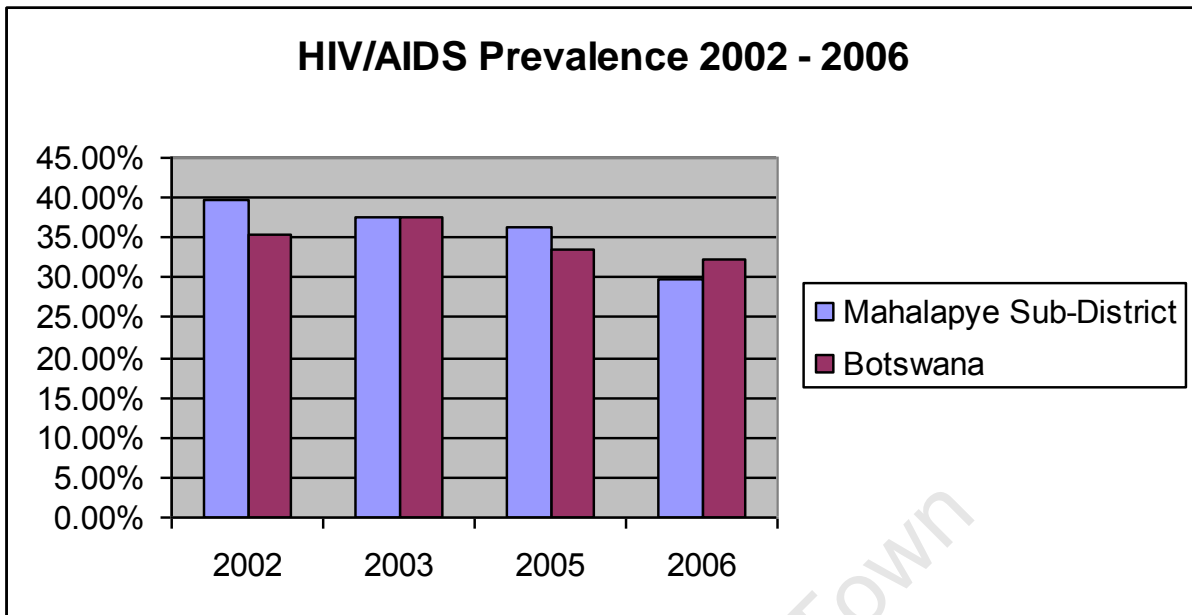
staffed by health workers who have limited diagnostic and treatment skills. People from rural areas have to travel long distances for specialised care (Republic of Botswana, 2000).

The provision of ARV therapy has widened the inequalities in access to treatment and care. The treatment was first introduced at the referral and two districts hospitals and later rolled out to all hospitals. This disadvantages rural communities because those people who could not afford to travel to treatment sites could not access treatment. The status of the programme is that it has been rolled out to some clinics in the country but people still have to travel to centrally located sites. In his 2003 discussion of the provision of ARV treatment in Southern Africa McCoy (2003) argued that the “choice to initiate treatment programmes in urban areas will effectively discriminate against rural populations”. He suggested that introducing treatment in areas that are difficult to reach would help to develop the health infrastructure and in the process reduce inequalities. This is contrary to what happened in Botswana where the focus of capacity development was on hospitals.

Overview of the HIV/AIDS Epidemic in Botswana

Botswana has been conducting sentinel surveys among pregnant women attending antenatal care in public health facilities since 1992. Since then the HIV prevalence among pregnant women has shown an upward trend (Figure 2). The prevalence was 18% in 1992 and by 2003 it had reached 37.4% before showing a decline in 2005 to 33.4% and a further decline in 2006 to 32.4 per cent. HIV prevalence among pregnant women varies by district. According to the 2006 survey, Chobe district had the highest prevalence (42%). The lowest prevalence of 19.1% was recorded at Kgalagadi. Even though there are geographical differences, the prevalence is generally high with most districts having a prevalence of over 20% among pregnant women. Prevalence rates have been slightly lower in rural areas than in urban areas. The HIV prevalence amongst pregnant women in Mahalapye, though still high, has declined from 40% in 2002 to 29.9% in 2006 (Masupu, et al., 2003; de La Hoz Gomez, et al., 2006).

Figure 2: HIV/AIDS Prevalence 2002-2006

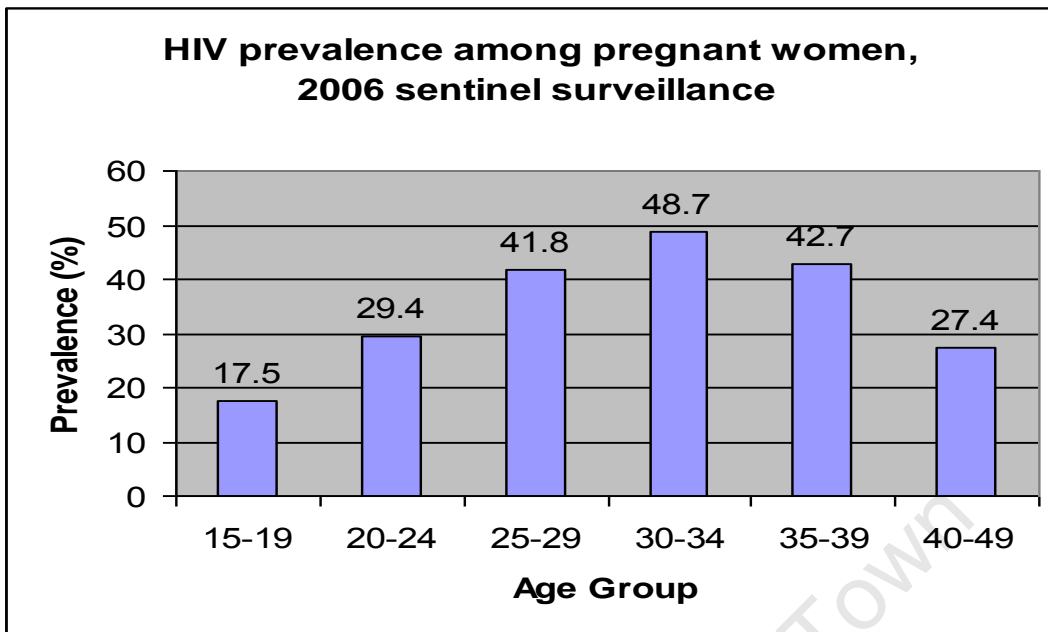


Source: Botswana Second Generation HIV/AIDS Surveillance

(2002), (2003), (2005), and (2006)

The distribution of HIV prevalence also differs by age groups (Figure 3). In 2006, the highest prevalence (48.7%) among pregnant women was in the 30-34 age group while the 15-19 cohort recorded the lowest rate at 17.5%. This represents a 7.2% decline since 2001 (prevalence 24.7%). The decline is attributed to behaviour change among the youth. The high prevalence among pregnant women has led to high numbers of children being infected through mother to child transmission. This has led to policy initiatives such as prevention of mother to child transmission that was started in 1999 (de La Hoz Gomez, et al., 2006).

Figure 3 HIV Prevalence by Age Groups



Source: 2006 Botswana Second Generation HIV/AIDS Surveillance

Against this background of high levels of poverty, a health system that favours urban areas and a concerted effort to make ARV therapy available to all who need it, this study focused on the difficulties faced by caregivers in accessing treatment for children under their care. It focused on the difficulties from the perspective of the user of the services.

CHAPTER 3

LITERATURE REVIEW

The commitment of the government to provide ARV therapy in the public sector has great potential to save lives. However, for treatment to be successful, it is important to understand factors that may present obstacles to success that lie outside the health system. This chapter will focus on issues related to the HIV/AIDS care-giving environment.

Poverty and HIV/AIDS

Evidence from literature has shown that poverty is a crucial factor in the spread of HIV/AIDS. Poverty is viewed as both a risk factor and a consequence of HIV/AIDS. Poverty is associated with poor housing, low levels of education, unemployment, poor nutrition and poor access to health care. Different dimensions of poverty reinforce each. For example, low level of education leads to low income and this affects the ability of individuals to sustain themselves and their families. Poverty is also associated with poor nutrition which increases susceptibility to HIV transmission and progression to AIDS. Poor access to health care services and low levels of education may mean that some poor people are not reached by HIV/AIDS education messages (Cohen, 1998; UNDP, 2000; Barnett and Whiteside, 2002; Siphambe, 2003)

Stillwaggon (2005) argues that the spread of HIV/AIDS cannot be explained by behavioural factors alone. She contends that vulnerability to disease is influenced by the strength of the immune system, which in turn is affected by factors such as nutrition, presence of parasites and other infections. She argues that poor nutrition increases vulnerability to diseases including HIV/AIDS, because it weakens the ability of the immune system to respond to infections. She further points out that micro-nutrient deficiency such as vitamin A deficiency undermines the integrity of the skin and mucous membranes and in that way increases vulnerability to infections. She asserts that the spread of HIV/AIDS is high among the poor of poor nations because "they are already immune comprised due to malnutrition, parasites or other infection". She states that parasites worsen malnutrition by draining nutrients from the body. She concludes that the HIV epidemic has spread because of "declining economies, insecure food systems and inadequate investment in water, sanitation" and that poverty eradication should be key factor in addressing the epidemic (Stillwaggon, 2005:1).

The UNDP (2000) also argues that HIV/AIDS thrives in conditions of poverty and in the process deepens poverty because of the loss of income earners and the depletion of resources to care for the sick. HIV/AIDS kills income earners who in most cases support a significant number of dependents. This has a serious adverse effect at household level especially on the poorest households. HIV/AIDS can erode the social safety net that is normally provided by the family. This may mean that families have difficulty in taking care of vulnerable members and offering support to other families. Poverty affects more women than men. Notwithstanding women are usually the main caregivers in households (Cohen, 1998; UNDP, 2000).

The impact of poverty on children is characterized by malnutrition, stunted growth, poor school attendance and increased vulnerability to diseases. The children of the poor are more likely to become the poor of the next generation (Cohen, 1998; Barnett and Whiteside, 2002).

The economy of Botswana (until the recent recession) was buoyant. Botswana was defined as a middle-income country. However, the high revenue generated by diamond production masks the very marked inequalities that exist in the country. The overwhelming majority of the people of Botswana live in a state of abject poverty. A 2004 study on the impact of HIV/AIDS on poverty and inequality in Botswana concluded that HIV/AIDS had a direct impact on poverty. The study reported that poor households were more vulnerable to income loss than others because of HIV/AIDS related mortality. The study found that income earners had more dependents to support because of HIV/AIDS. This in turn exerted pressure on household resources. It predicted that destitution, which is defined as "households with no income earners", would increase in the country. Consequently the living standards of children in poor households would fall. This impact, the author argued would be more profound in poor households (Greener, 2004:177).

Rajaraman, et al., (2006) in their study on HIV/AIDS and economic survival in Botswana found that income loss resulted from taking unpaid leave, from job loss by caregivers and from the death of a breadwinner in the family. Consequently, food shortages, leading to poor nutrition and inability to meet the basic needs of the family, were common.

The government of Botswana has put in place commendable social welfare programmes to address poverty. The old age pension is offered to men and women aged 65 years and over. Food rations are given to the destitute and free health care is available for pregnant women

and children. In response to the economic impact of HIV/AIDS, the government has also introduced the orphan care programme. This programme provides support to households caring for orphaned children. Assistance consists of food rations, school uniforms and other school needs (Siphambe, 2003; Rajaraman, et al., 2006).

Treatment Related Costs

While ARV therapy is provided free of charge in the public health care system in Botswana, the cost of reaching the treatment site is high for many poor people. Currently, ARV treatment is provided in all hospitals in the country and a few clinics in towns and larger villages. This arrangement involves a lot of travelling for many people who live outside towns to centrally located facilities to access treatment. As a result, patients and caregivers may incur substantial treatment-related costs for transport and food (Kgathwane et al., 2006; Smart, 2005). In their study on the factors affecting adherence to ARV in Botswana, Kgathwane et al.(2006) found that 44% of respondents reported an increase in expenditure as a result of being on treatment. The same study reported that 12% of respondents had failed to go for their medical appointments because of lack of money for transport.

The findings of the Botswana study are supported by the findings of Nduhura et al., (2007) in their study in Tanzania. They concluded that treatment-related expenses were too high for most of the people and could affect adherence. They observed that patients were compelled to make several trips to the treatment centre for adherence counselling and diagnostic tests. They also observed that in a few cases of poor adherence the main reason was lack of money for transport.

Kgathwane et al. (2006) noted that patients experienced increased spending on food because of being on treatment. Caregivers stated that when they had financial difficulties they were forced to interrupt the child's treatment. When there was no food for the family some caregivers opted to interrupt treatment and instead buy food, (Kajura et al., 2006). Nduhura et al. (2007) also observed the financial constraints experienced by caregivers in their study in Tanzania. In that study, 88.1% of households sampled had to cut down on food expenditure and children's education to allow a member of the family to access ARV treatment.

Disclosure of the Child's HIV Status

Telling the child that s/he is HIV positive, disclosing to family members and to people outside the family is one of the difficult situations a caregiver has to face. Caregivers often grapple with the decision of when and how to disclose the child's status (Ward, 1999). Since most of the children contract HIV through prenatal transmission, caregivers may experience guilt and shame. They may not want to disclose their own status and they may fear stigma and as such have difficulties in discussing the child's diagnosis and the drugs s/he is taking (Jackson, 2002; Kajura et al., 2006). However, disclosure can have positive consequences. Support from family members, the community and other institutions such as churches and schools is likely to be forthcoming. Support may take various forms such as childcare, provision of medical information, material and emotional support (Serovich, 2001; and Klitzman et al., 2004).

Studies have shown that where disclosure had occurred adherence to ARV treatment was good (Klitzman et al., 2004; Kajura et al., 2006). Kajura et al., (2006:590) investigated disclosure of HIV status and adherence amongst children in Uganda and observed that children who had been informed of their diagnosis were "self-motivated" to adhere to treatment. Caregivers and children (ages 5-17 years) in this study viewed adherence to treatment as a "shared responsibility". Where disclosure had occurred, children, especially the older ones, were less dependent on caregivers and instead found ways of remaining on medication such as taking the treatment on their own at school. Children in this category were motivated to adhere because they understood the benefits of taking treatment regularly and the disadvantages of poor adherence. The researchers concluded that where there was disclosure, there was also a supportive parent child relationship.

Kajura et al., (2006) on the other hand observed that in a situation of non-disclosure children are dependent on caregivers to take treatment. They are not motivated to take treatment regularly because they do not know why they must take it. The researchers observed that children in this group would use any opportunity they had to miss treatment, such as when the caregiver was absent (Klitzman et al., 2004; Kajura, et al., 2006).

HIV/AIDS Stigma and Care Giving

One of the issues that HIV affected households have to deal with is that of HIV/AIDS stigma. Herek et al., (1998:1), describe AIDS stigma as "prejudice, discounting, discrediting, and

discrimination directed at people perceived to have HIV or AIDS". Because of these perceptions, people living with HIV/AIDS are sometimes discriminated against and treated as outcasts by society. Stigma and discrimination associated with HIV/AIDS stems from fear of contracting HIV through social contact and the misconception that people living with HIV/AIDS acquired it through sexual immorality (Herek, Widaman, and Capitanio, 2005; Cao et al., 2006) This exaggerated risk of contracting HIV is what Herek; Widaman and Capitanio (2006:16) refer to as "instrumental stigma". Stigma can have a negative impact on patients and caregivers. For example, Mills (2006) observed that people in KTC settlement in the Western Cape, South Africa, were not willing to use local health facilities, but would prefer to travel long distances to places where they would not be recognized. The same phenomenon has been observed by Ware, Wyatt, and Tugenberg (2006), in Boston, USA and Nduhura et al., (2007) in Tanzania.

Stigma also affects disclosure of an HIV positive status. The caregiver may be reluctant to seek help from family members and other support systems available in the community in order to avoid disclosure and thus protect the infected person against anticipated recrimination (Cao et al. 2006; Ware, Wyatt, and Tugenberg 2006). This means that the affected household may be isolated and have no support. This was also observed by Akintola (2004:32) when he analyzed the burden of care on caregivers in South Africa and Uganda.

"People living with HIV are discriminated against and neglected by their family members because of stigma prevalent in their communities. Caregivers in many cases bear alone the burden of caring for the sick because of fear of leaking the status of their patients to the neighbours."

Stigma directed against households affected by HIV/AIDS was also observed by More and Henry (2005) in a study in Togo. They explored the experiences of caregivers of people living with HIV/AIDS and concluded that the affected households were stigmatized by extended family members who would avoid contact with them and thus deny them support. In an effort to conceal their HIV status and thus avoid being stigmatized patients and caregivers would avoid being seen with ARV drugs. They would put them in containers that were less stigmatizing and miss doses if they were in the company of friends and relatives (Klitzman, et al., 2004; Cao et al., 2006; Ware, Wyatt, and Tugenberg, 2006).

However, some studies have reported a decrease in the level of stigma. They assert that stigma is less pronounced than in the earlier years of the epidemic. Castro and Farmer (2005: 57) dispute the commonly held view that stigma is a barrier to accessing services. They assert that the obstacle to accessing services has to do with economic and logistical issues such as poverty. In their study in Haiti, they observed that the introduction of ARV therapy helped to reduce HIV/AIDS related stigma. They state that "the transformation of AIDS from an inevitably fatal disease to a chronic and manageable one has decreased stigma drastically". They contend that improved care has the potential to lessen stigma.

Drug Related Issues

The goal of ARV treatment is to improve quality of life and prolong survival by suppressing the replication of the HIV virus. As such, one of the issues which the caregiver has to deal with is to administer drugs at prescribed intervals and at specific times over a long period of time. Failure to comply with these conditions may lead to treatment failure (Ward, 1999; Byrne and Honig, 2006). According to Stevens, Kaye and Corrah, (2004), timing of dose taking is crucial in order to maintain a regular concentration of the drug in the body. If a dose is delayed or treatment is interrupted, the drug concentration falls and this creates a situation that is conducive for the replication of the virus which may subsequently cause drug resistance and treatment failure. Yet caregivers may face difficulties in drug dosing and timing. This was observed by Kajura et al., (2006) in Uganda. They reported that 17% of caregivers stated that children had missed doses because of forgetfulness; caregivers being busy with other household duties.

Apart from making sure that the child takes her/his drugs as prescribed, caregivers are expected to continuously monitor the child for any side effects. Children are normally put on a combination of drugs that have various side effects such as rashes, nausea, vomiting, and mood changes. It is assumed that the caregiver will know about the side effects of the drugs the child is taking (Idoko et al., 2006).

The Burden of Care

Many studies have shown that the burden of care for people living with HIV/AIDS is mostly supported by women. For example, Simpson's (2006) study of caregivers in South Africa observed that the majority of caregivers were women. Of the 42 care providers who were

interviewed in the study, only five were men. Akintola (2004:4) sums up the situation when he says:

"The burden of caring for the sick weighs disproportionately on women, not only because they are the main providers of care in the homes, but also because many have lost their male partners, or have never been married, and, therefore, have to bear alone the financial costs of caring for self and sick family members."

Caring for a person living with HIV/AIDS is stressful and demanding. The stressful situations experienced by the care provider may affect the ability to care if they are not addressed. Akintola (2004:23) identified four types of stress experienced by care providers.

Caregivers experienced physical stress that was characterized, among other things, by chronic fatigue, headache, and chronic backache. The source of physical stress was doing household activities and duties for the sick person.

Care giving exposes care providers to psychological and emotional stress. This might be caused by the fear and anxiety of dealing with a positive diagnosis, stigma, discrimination, and witnessing frequent deaths of other family members. It may also be due to the fact that the caregiver may also be HIV positive and as such may be grappling with the same health problems (Wight, Leblanc, and Aneshensel, 1995; Akintola, 2004; Hunter, 2007).

Economic stress was another characteristic of caregivers. This was caused by increased costs of food, transportation of the sick person to health facilities and loss of job opportunities. In their study of extended family caring for children orphaned by AIDS in Botswana, Heyman, et al., (2007) observed that one-third of the working adults were caring for orphans with limited resources and as a result could not meet their needs.

Support System

The above discussion has highlighted the problems faced by caregivers. Caregivers need a support system to help them cope with stressful situations. Support systems might include extended family, health and welfare professionals, churches, and caregiver support groups, (Jackson, 2002; O'Hare, et al., 2008).

An extended family can be a strong source of support, if the diagnosis of the HIV positive person is accepted, even though this social safety net has often already been weakened by

HIV/AIDS. Extended family members may help by mobilizing resources for the affected family; help with childcare and household chores. Family support can also help by sharing responsibility for administering the child's treatment. Support from the extended family may serve as a motivating factor to continue providing care (Wight, Leblanc, and Aneshensel, 1995; Shah, 2007).

Rajaraman (2006) and Heyman, et al., (2007) study in Botswana found that relatives were generally the main source of support to affected families. However, some studies have reported reduced support from the extended family due to HIV/AIDS. Death of family breadwinners had reduced sources of income which were used to support the extended family. The meagre household resources were stretched to the absolute limit and there were no more material resources to be given.

Support groups for people living with HIV/AIDS (PLWHA) or for people caring for adults or children with HIV/AIDS have been found to help relieve stress. Support groups provide for a forum to meet other people who are facing the same problems. Sharing experiences can help to allay anxieties that caregivers have and give them the strength to continue providing care. Support groups are also important because they empower caregivers by educating them. They share ideas on how to handle common problems encountered in care provision. Meeting other people helps to increase confidence and helps carers to realise that they are not alone (Jackson, 2002; O'Hare et al., 2008). However, care providers may not use such services for fear of exposing their HIV status or that of the person for whom they are caring. In Botswana, Jacques and Stegling (2004) found that food and material assistance for patients on Home Based Care were not utilized because of stigma.

Faith Based Organizations (FBOs) are an important support system in many communities regardless of people's religious affiliation. They have a potential to reach many people because in most cases they are the only non-governmental organizations (NGOs) found in rural areas. FBOs have been found to provide a continuum of care from prevention, treatment and care. They provide spiritual care, counselling, care for vulnerable children and palliative care. In an effort to alleviate poverty experienced by caregivers, many have started income generation projects for people living or affected by HIV/AIDS (Green, 2003; Moore & Henry, 2005; UNAIDS, 2006a).

UNAIDS (2006a) describes the support provided by the Catholic Church through the "choose to care" initiative in Botswana, Lesotho, South Africa and Swaziland. The initiative started Home Based Care programmes for people living with HIV/AIDS (PLWHA) and later incorporated the care of orphans and vulnerable children. The church provides day care services and food to PLWHA and vulnerable children cared for by elderly relatives. Day care services reduce the burden on caregivers and this gives them the chance to attend to other household tasks. The initiative also helps children to continue with their education by shouldering school-related costs. Families who have orphans are also assisted financially to meet the basic needs of the children. This is also done through creation of income generating projects for caregivers (UNAIDS, 2006a). Nevertheless, Simpson (2006) found that while the church was the most accessible support system for most people only 55% of caregivers in her South African study were using it.

Orner (2006) investigated the psychosocial impacts on caregivers of people with AIDS in South Africa. She found that NGOs were particularly valued by the carers for the home visits they offered. They were able to meet the needs that could not be addressed through the health system. NGOs provided material support such as groceries which were desperately needed in most of the households. They also provided counselling to PLWHA and care providers and helped with cleaning and cooking in the household. Those who received support associated it with "improved psychosocial status". This shows the positive impact that support can have on the morale of the care providers. This can be a source of strength to continue providing care in the midst of all the hardships.

Some studies have shown that government departments are the main sources of support for caregivers. Caregivers mostly use the public health sector for counselling, HIV/AIDS information, treatment of opportunistic infections and accessing ARV therapy. In South Africa the Department of Social Development plays a crucial support role because this is where caregivers access social assistance such as Child Support grants, disability grants and Foster care grants (Orner, 2006; Kane, 2008).

It is evident from the literature that care providers are grappling with a number of issues in their care giving roles. It has been highlighted that care giving has enormous physical and emotional challenges. Caregivers have to contend with the rising cost of living amid poverty that is prevalent in most households; which deepens with the costs of caring. The other key

issues that emerged in the literature were stigma and/or fear of it, and the fact that women, who are often the poorest people in a community, were the primary caregivers.

Based on these insights drawn from the literature, chapter 5 will examine the situation faced by caregivers in Mahalapye. However, before taking this discussion forward it is necessary to reflect on HIV/AIDS policy and the ARV policy in Botswana. Chapter 4 takes up this discussion.

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CHAPTER 4

THE POLICY PROCESS: THEORETICAL FRAMEWORKS

HIV/AIDS has become a major developmental challenge in Botswana because of its cross-cutting impacts on society. The high prevalence rates have led to a rise in mortality especially of young adults. This has in turn caused a fall in the average life expectancy. In addition, the health care system has been overstretched because of the high demand for services. A large portion of the budget for the health sector is devoted to provision of care, treatment and support for people living with or affected by HIV/AIDS. Furthermore, the country has experienced a rise in the number of orphans and this has exerted pressure on the social support systems. At the household level, families experience loss of income due to a rise in health related expenditure and the death of income earners (Poku, 2005; NACA/UNDP, 2006)

It is therefore critical to have a supportive policy environment to direct implementation of prevention, care and treatment programmes. A national HIV/AIDS policy is important because it gives direction to the country's response and demonstrates the government's commitment. When a policy is in place, it is used as a guide by various stakeholders to develop strategic plans and implementation guidelines. National HIV/AIDS policies are also needed to mobilize resources (financial, human and material) for the effective implementation of interventions aimed at attaining the objectives set (Stover and Johnston, 1999; Dirwayi, et al., 2004).

The purpose of this chapter is to outline Botswana's HIV/AIDS policy in the context of ARV therapy. To contextualise this discussion this chapter will first discuss different understandings of policy and then look at some key concepts in the policy process.

Dye (1975:3) defines public policy as "whatever governments choose to do or not to do". Anderson (1975) cited by Walt (1994:41) defines policy as "a purposive course of action followed by an actor or a set of actors in dealing with a problem or a matter of concern". Even though there are differences in definitions, Walt (1994) and Birkland (2005) describe the common attributes of policy as: a decision taken by government in response to a problem affecting society; a course of action directed at attaining a goal. Policy gives an overview of what should be done and specifies the roles and responsibilities of various stakeholders.

Types of Policies

There are various ways of classifying policy. This discussion will focus on Walt's typology of policies according to their effect. She identified four types of policies; distributive, regulatory, self regulatory and re-distributive. Distributive policies relate to provision of services to certain groups in society such as free ten year basic education for children. These kinds of policies are not considered to be controversial because they do not disadvantage other groups. The second type of policy is the regulatory policies which are aimed at controlling the behaviour or professional practice of particular groups such as the licensing of doctors. Self-regulatory policies are developed by organizations in order to protect their interests, such as codes of practice. The fourth type of policy according to effect is re-distributive policy. These are highly controversial policies because the government makes a deliberate decision to address the socio-economic inequalities in society by improving the status of certain groups at the expense of others. These types of policies may generate a lot of opposition from various interests groups and individuals (Walt, 1994).

There are specific processes that are followed when developing policy. These processes are influenced by different theoretical frameworks and models. One of these models is the elite model. This model suggests that policy decisions are taken by a small group of people who have power. It contends that policy is influenced by the preferences of the elite with little input from the masses. In order to maintain their dominance the elites may resist radical policy changes that could erode their power, but may opt for incremental changes. Elite theory suggests that the masses are "passive, apathetic and ill informed" and merely receive decisions and directions from the top. The implication of this theory is that policy does not represent the needs and interests of the public but of a few individuals or groups (Dye, 1975:27; de Coning and Cloete, 2006).

Another important theory of policy making is the group model. The emphasis here is on the role of interest groups in policy decisions. The main role of interest groups is to advocate for their own interests at any or all stages of the policy process. The extent to which groups can influence the policy process is determined by factors such as the strength of the organization, expertise and access to decision makers. Since policy decisions are influenced by various interest groups the implication is that the policy outcome is a product of intense debate, lobbying, bargaining and compromise amongst competing ideas (Dye, 1975; Walt, 1994; de Coning and Cloete, 2006).

The systems approach suggests that policy is linked to the political system in the country. The political system determines the extent of participation in policy making. For example, liberal democracies encourage direct or indirect involvement while an authoritarian system may formulate policies without the input of the public. The focus of the systems model is on the ability of the political system to respond to the demands in its environment. The ability of the political system to respond to the demands is influenced by factors such as availability of resources and public support. These demands may be generated by individuals or by groups pushing for policies of their preference. For example, interest groups have in the past pressurized their governments to provide ARV therapy or Prevention of Mother to Child Transmission (PMTCT) services in the public sector. As such, this model recognizes the contributions of other stakeholders in the policy making process and it views public policy as "an output of a political system". This model may be relevant to the HIV/AIDS treatment policy in Botswana, which was a product of extensive consultation with national and international stakeholders (Dye, 1975:, 37-38; Walt, 1994; de Coning and Cloete, 2006).

Policy models incorporate different phases that an issue has to pass through before consensus is reached. Notwithstanding some differences, broadly speaking the policy process consists of problem identification, agenda setting, policy formulation, policy implementation and policy evaluation (Walt, 1994). Problem identification or agenda setting is the first phase of the policy making process. Cloete and Meyer (2006:107) view policy agenda setting as a "deliberate planning and action process through which policy issues and problems are identified, defined, structured, prioritized, support mobilized and decision makers lobbied to take appropriate action". This definition demonstrates that policy makers normally have many problems to address through policy and this necessitates the need to prioritize issues. Prioritizing problems is also influenced by the fact that governments do not have enough resources to tackle all the problems on the agenda at the same time. Agenda setting (the debate or struggle about priorities) helps to narrow down the number of issues to be discussed. Cloete and Meyer (2006:109) assert that some problems enter the policy agenda when they have a wide impact and when they have reached "crisis proportion" and can no longer be ignored by government.

This was apparent in Botswana where, by the later 1990s, HIV/AIDS had reached crisis proportions. The high prevalence amongst the adult population had led to increased morbidity

and mortality amongst the economically productive age group. With their premature deaths many of the skills needed to develop the country also died. The 2001 census recorded a 62% increase in mortality rates. The other impact was the decline in life expectancy from 65.3 in 1991 to 55.6 in 2001. Because of the high prevalence rate and hence the increasing demand for services the health care system has been overstretched. One of the social impacts of HIV/AIDS was a growing population of orphans. These factors compelled the authorities to put provision of ARV therapy onto the policy agenda (Republic of Botswana, 2000; Republic of Botswana 2001; UNDP, 2001).

The Hall model, as discussed by Walt (1994), proposes legitimacy, feasibility and support as the main conditions that determine whether an issue qualifies to be placed on the policy agenda.

Legitimacy refers to a government's view that it has the right to intervene in a situation and that most people would support the intervention. This was applicable in Botswana because without treatment many young adults were dying in the prime of their lives. The devastating impact of HIV/AIDS on the population forced the government to consider provision of ARV therapy in the public sector.

Feasibility refers to the capacity of the government to intervene and this is determined by the availability of resources (financial, human and technical) and the necessary infrastructure (Walt, 1994). The capacity of the government to implement ARV therapy in the public sector was one of the factors that were seriously considered during policy discussions. A feasibility study was conducted to assess the potential of implementing the programme. The assessment identified serious resource constraints but recommended that it was possible to start ARV therapy in the public health sector using a phased approach. The results of the feasibility study were used to develop a strategic plan to address the gaps identified (de Korte, et al., 2004).

Public support for a policy is crucial for any government. If there is strong opposition to reforms, the government may have difficulties implementing such a policy. Introducing policies that are not supported by the public may lead to demonstrations aimed at weakening the government. Therefore, it is important for government to assess the level of support for a proposed reform. This assessment helps government to mobilize those who support the policy

and to devise strategies to address the threats of opposing groups. Strategies might include media campaigns to convince the public to support policy or delay implementation (Walt, 1994).

The government of Botswana had strong public support for introducing ARV therapy. This can be attributed to the impact of the epidemic on the population. The government also enjoyed considerable support from international agencies and donors (de Korte, et al., 2004).

Public participation is a crucial component of the policy process. Involvement of the public is important because it builds ownership of the policy. Participation may include individuals, interest groups and organizations. Cloete and Meyer (2006) have identified four ways in which the public may be involved in the policy process as:

- Ratification – This means endorsing decisions that have been taken by the authorities. Although this is considered as a form of involvement, the public cannot change the nature of the decision unless they elect a new government.
- Consultation – This involves soliciting advice, opinions, suggestions and recommendations about an issue before a decision is made. This gives the public an opportunity to debate issues in the hope of influencing policy decisions. This can only be an effective method of community involvement if the authorities take the views of the public seriously. This is because decision makers are not obliged to consider the views generated through the consultative process.
- Negotiations – This involves direct participation in discussions. This method gives the public an opportunity to influence decision making through bargaining and compromise.
- Execution – The public is involved during planning, implementation and evaluation of policy programmes.

Actors in the Policy Process

The policy process involves multiple stakeholders who may support or oppose a reform. As such, it is important to identify key stakeholders who have a vested interest in the agenda item. Relevant policy actors may include those within or outside government and international agencies. Identifying key actors in the policy process is important because it

helps policy makers to find ways of “selling” the policy to those who may support and those who may oppose it (Walt, 1994; Stover and Johnston, 1999).

Walt and Gilson (1994) as cited by Stover and Johnston (1999) have identified five key actors in the policy process as:

- Technocrats - This group includes scientists, academics, public professionals who provide technical information on the magnitude of the problem, its cause, possible impacts and solutions. In reference to HIV/AIDS, the information could include prevalence and mortality rates, bed occupancy rates and the number of orphans as well as other information needed to develop a feasible policy.
- Bureaucrats who may provide an analysis of the capacity (finance, manpower, technology and infrastructure) of government structures to address the problem.
- Interest groups that represent the interest of particular sections of society. The aim of interest groups is to ensure that their concerns are considered in policy decisions. Particular interest groups in HIV/AIDS are networks of people living with HIV/AIDS and human rights groups such as the Botswana Network of People Living with HIV/AIDS and BONELA (Botswana Network of Ethics, Law and HIV/AIDS).
- Politicians who are the ultimate decision makers.
- Donors have a great influence in policy formulation and implementation. Donors may support the policy process with financial and technical expertise. In the case of ARV therapy in Botswana, many international agencies such as UNDP, UNAIDS and Botswana Harvard Partnership have and are still playing a crucial role in policy formulation and implementation. One of the key partners is the African Comprehensive HIV/AIDS Partnership (ACHAP), which is a public-private partnership between the government of Botswana, The Bill and Melinda Gates Foundation, the Merck Company Foundation and the Sharp and Dohma (MSD) Pharmaceutical Company. The pharmaceutical company has donated two ARV drugs while the two foundations have each committed US\$50 million each. ACHAP funded the recruitment of the operational manager, recruitment and training of health workers, establishment of an IT-based patient management system, and increased laboratory and storage capacity (de Korte, et al., 2004; Poku, 2005).

Managing Policy Implementation

The impact of any policy can only be tested through implementation. Brynard and de Coning (2006:183) define implementation as the "conversion of mainly physical and financial resources into concrete service delivery outputs in the form of facilities and services or into other concrete outputs aimed at achieving policy objectives". This definition demonstrates that implementation is a complex phase in the policy process that needs to be managed properly because it involves a lot of resources and multiple stakeholders. It is also important to determine how policy implementation will be undertaken.

In Botswana, the government adopted a phased approach in the implementation of the ARV programme. This was based on geographical demand and clinical criteria. The advantage of a phased approach is that lessons learnt during the early stages of implementation can be used to improve service delivery during the later stages. In addition, the phased approach allowed the public to become familiar with the new service. It also provided an opportunity for government to gradually build the capacity of the health system before rollout to other sites (MOH, 2003; de Korte, et al., 2004; Poku, 2005). To sustain implementation government had to mobilize financial, technical and technological resources to build the capacity of health system.

An Overview of the History of HIV/AIDS Policy in Botswana

The first national HIV/AIDS policy in Botswana was developed in 1992 and was revised in 1998. The revision was necessitated by the need to address emerging policy issues identified during implementation and to keep pace with scientific developments in the field of HIV/AIDS. The national HIV/AIDS policy was implemented through the Medium Term Plan I (MTP I) which ran from 1989 to 1993 and MTP II which was from 1997 to 2002. MTP II advocated for a multi-sectoral approach involving non-governmental organizations, the public and private sectors. During this phase, several structures at national and district level were put in place to manage and coordinate the response. MTP II also witnessed the introduction of the national ARV programme in Botswana. Currently, the response is guided by the National Strategic Framework 2003-2009 (MOH, 1998; UNDP, 2000; Republic of Botswana, 2003b; Kgathwane, et al., 2005). One of the key thematic areas of the National Strategic Framework is treatment, care and support for those infected and affected. Intervention programmes that address this element include amongst others provision of ARV

therapy. Another goal is to mitigate the socio-economic impact of epidemic. This includes support for orphans and provision of counselling services (Republic of Botswana, 2003b).

Botswana's national ARV programme was based on universal access to treatment. Called MASA, a Setswana word for new dawn, it began in January 2002. The programme falls in the category of distributive policies. It targets everybody living with HIV/AIDS. It is not controversial because it does not disadvantage any group. It was started at Princess Marina Hospital (the main hospital in Gaborone) and was later rolled-out to three other sites during the course of the year. The programme was subsequently rolled out to all the districts (all referral, district and primary hospitals, two mining hospitals, two mission hospitals and three Botswana Defence Force health facilities) in the following three years (MOH, 2003; de Korte et al., 2004; Smart, 2005).

As of April 2008, there were 100, 517 people on treatment of whom 9,514 accessed treatment from the private sector. The private sector is mostly used by those who have medical insurance and those who have the financial means. There were 6,481 children on treatment, representing 8% of all those on treatment. Sixty seven percent of those on treatment were women (Macheo, 2008).

To build the capacity of the health system to be able to provide ARV therapy, six critical work streams were identified. These were:

- Recruitment and training of health care workers. Botswana has chronic shortages of health personnel and addressing this concern was a critical factor in the provision of ARV therapy. Existing health personnel lacked experience with ARV therapy. The training needs were addressed by developing training modules on ARV therapy that were used to train health workers.
- Building the testing and laboratory capacity for testing. The expansion was addressed through collaboration with international partners who provided resources such as construction of laboratory facilities, transport, fridges and machinery.
- Counselling and Community Mobilization – This work stream developed educational tools on ARV therapy targeting the patients, family and the community. Mobilization involved various stakeholders such as support groups of people living with HIV/AIDS, faith based organizations, traditional healers and the media.

- Drug Distribution – ARV drugs are ordered from Central Medical Stores (CMS), which is responsible for procurement of drugs from manufacturers for distribution to public health facilities. All approved treatment sites order drugs from CMS and are expected to have sufficient quantities of drugs in stock. This implies that patients in facilities not approved to dispense ARV drugs must access them at the nearest treatment site (de Korte et al., 2004). Pharmacy staff is expected to continuously review the stock of ARV drugs to guard against interruption of supply. To do this they have to maintain a daily stock book that shows the level of drugs available. They also have to maintain a daily dispensing book that shows daily consumption (MOH, 2008).

One of the contentious issues in the management of ARV drugs is security. Authorities must ensure that there is no theft of drugs which can later be sold on the black market. Uncontrolled use of ARVs is almost certain to lead to drug resistance. To strengthen security and accountability the MOH decided to apply the protocols used for managing habit-forming drugs to ARVs. This means that only a limited number of people have access to the drugs (MOH, 2003).

- Upgrading of Physical Infrastructure – Provision of ARV therapy is out-patient based, therefore, additional space was required for consultation, counselling, dispensing and to provide waiting areas. To alleviate the shortage of space portable units were built in all treatment sites where there was an acute shortage of space.
- Establishing a patient-based management system that could track a patient's appointments, drug utilization and key clinical and laboratory information was an innovation of the programme. Since none of the existing health facilities were using such a system, there was extensive training of staff to build capacity (MOH, 2003; de Korte, et al., 2004)

National HIV/AIDS Treatment Guidelines

A key part of Botswana's ARV policy was to develop treatment guidelines and protocols for service providers. The treatment guidelines give direction on the management of HIV/AIDS. Apart from clinical criteria, the guidelines also specify the factors that should be considered before starting children on ARV therapy (MOH, 2008:63).

- The caregiver should be prepared to actively participate in the care and treatment of the child.
- Health workers should identify the primary caregivers who will be responsible for giving the child medications and supervising adherence.
- Health workers should determine the caregiver's knowledge of the medical regimen and help the caregiver to understand it.
- The health worker must ascertain who will ensure medication adherence if the primary caregiver is absent.
- Health workers must discuss with the caregiver the child's understanding of the medication and his/her HIV status.

It is evident that the ARV policy places considerable demands on the caregiver. The guidelines emphasize that the caregiver should be committed to participate in the care process. However, the policy does not discuss the support mechanisms available to address issues that lie outside the health system which may have a direct impact on adherence. It is also evident that the guidelines emphasis is on managing the clinical aspect of the infection without paying attention to structural factors such as poverty and distance to health facilities. These factors have the potential to negatively impact on the successful implementation of the policy.

UNICEF (2005:7) has noted that "poverty limits the capacity of families and individuals to care for household members." These demands are difficult to meet without additional support to households. It is therefore imperative to explore how households are coping with these challenges and how this has affected their care giving roles. One argument of this thesis is that the policy process should be re-conceptualized to include the perspectives of people on treatment and caregivers. Just as a broken supply chain within the system can have negative effects, so can the inability of caregivers to take children to the clinic also have detrimental consequences.

CHAPTER 5

THE STUDY

The aim of this study was to explore the lived experiences of caregivers of children who are on ARV therapy and the implications for policy. As I have argued, policy, which sees the health service as a closed system, may be neglecting crucial factors that can undermine the success of the policy. If this is found to be the case, there is a strong argument for looking beyond the health service to design policies, which also embrace the difficulties that users of the health service face in accessing treatment, and maintaining it. The literature review identified the main areas of difficulty faced by caregivers. The following chapters of this thesis investigated these issues in the empirical context of Mahalapye, Botswana.

Study Setting

Mahalapye Sub-District, the area where the study took place is one of the six Sub-Districts of the Central District and consists of 40 villages. The Sub-District is mainly a rural one with some semi-urban areas with a total population of 108,811. The Sub-District has forty-four health facilities including a district hospital and a primary-level hospital. Mahalapye village is the administrative centre of the Sub-District where the main council and government offices are located. The village also serves as the headquarters of Botswana Railways. Mahalapye Village lies 200 kilometres north of the capital along the A1 road that is used as the cross-national and regional trucking route throughout southern Africa (Kgathwane et al., 2005; Mahalapye Sub-District, 2006).

Mahalapye Sub-District was chosen as the study site because it is an area of high HIV prevalence. In 2005, the prevalence among pregnant women was 33.4%. In 2006, prevalence seemed to have declined to 29.9%, The national rate was 32.4% (de La Gomez et al., 2006). The study population was drawn from staff and caregivers of children taking ARV therapy at Mahalapye Hospital Infectious Disease Control Clinic. Mahalapye hospital is a 250-bed hospital and it started providing ARV therapy in October 2003. Provision of ARV therapy for children has been integrated into the adult treatment centre.

Study Population

The focus of my interest in this study was on the caregivers of children who are on ARV therapy. My study population included primary and secondary caregivers. Only primary caregivers of children who were on ARV therapy and who were willing to participate were included in the study. Caregivers whose children had not yet started ARV therapy were not part of the study.

Secondary caregivers (nurses, social workers and counsellors) were targeted because they have regular contact with primary caregivers. The assumption was that health workers are familiar with the challenges faced by the caregivers of children who are on ARV therapy. These key respondents gave information on how they have in the past handled challenges faced by caregivers especially those that might potentially negatively affect the treatment process. The information provided by key informants was also used to cross check the information provided by the primary caregivers.

Sampling

Since it was not possible to study the whole population of caregivers at the treatment centre because of time and resource constraints, purposive sampling was employed in the study. Purposive sampling is a type of non-probability sampling method that is based on the judgment of the researcher. This sampling method allows the researcher to work with respondents who meet the criteria of the study. Purposive sampling allows the researcher to “handpick the sample based on knowledge of the phenomena of study” (Brink, 2002: 141; Bless, et al, 2006).

I used non-probability sampling knowing that the chosen sample would not be representative of the population of people on ARVs. Rather, the findings are only representative of the sample in this study and cannot be generalized. However, the research will raise questions that can be studied further by other researchers because this area is similar to many others in rural Botswana and the lives people live are also very similar. Hence, although not a representative sample I am confident that some of the issues that emerge from the research will resonate with experiences of caregivers in other parts of the country. It is for this reason that the research is exploratory. Further studies will be able to apply this methodology and test my findings in other areas using a representative sample.

Purposive sampling allowed me to identify respondents based on my judgment. For example in situations where the child was accompanied by somebody who was not living with the child, such a caregiver was not recruited to take part in the study. There were instances where the primary caregiver had asked a neighbour or distant relative (who did not live with the child) to take the child to the hospital. Since I wanted to hear the perspectives of both men and women concerning care giving I had to wait for a long time to find men to interview. I also wanted my sample to be diverse in terms of area of residence within the entire Mahalapye Sub-District. Targeting respondents from different villages and sexes helped to gain multiple perspectives of caregivers' experiences.

The sample for this study consisted of five primary (two men and three women) and four secondary (one man and three women) caregivers who were recruited for in-depth interviews. I chose five primary caregivers for in-depth interviews because by the fifth person the information was becoming repetitive.

For the quantitative component, a sample of forty-nine primary caregivers was drawn from a population of 492. This is 10% of the population. This was not a representative sample because it was not randomly selected. The primary caregivers were identified when they accompanied children to the treatment centre for medical reviews. I relied on the health personnel to identify caregivers

Research Design

The study combined qualitative and quantitative research methods to collect data from respondents. The advantage of mixing qualitative and quantitative research methods is that it helps to cross check the findings. This combination, which is referred to as triangulation, helps to compensate for the shortcomings of each of the methods (Baumgartner and Strong, 1994; Brink, 2002). According to Denzin (1978) cited by Baumgartner and Strong (1994:186) triangulation can be used for "cross validation" of research methods. Triangulation is the term that is used when data is collected using different approaches and methods. . For example, the researcher could use interviews or observation and the data from one source could be checked against the other. For this study I used a questionnaire, in-depth interviews and observations to cross check the accuracy of the information provided by respondents. Observations were particularly vital when I visited the homes of those who participated in the in-depth interviews. I was able to see things which I would not have

known just from listening to the interviews at the hospital. For example, most of the respondents reported that they were poor, but their appearance did not portray any signs of poverty. This is because people always wear their best clothes they go to the hospital. It was only when I visited their homes that I saw the dismal conditions under which they were living

Qualitative Research Design

The qualitative method was used in this study because it is an approach that promotes deeper understanding of people's experiences and perceptions. Qualitative research, also known as the interpretive paradigm approach, focuses on the lived experiences of participants and how they make sense of their lives. This method is very useful for telling the story from the view point of the participant. The method is able to produce detailed information on how people feel and think about an issue that is being investigated. Since this method explores issues in detail, it is relevant when the researcher wants to understand the behaviour of people. Qualitative research allows the researcher to describe situations, people's attitudes and perceptions regarding a particular phenomenon. Since the focus of qualitative research is on lived experiences it helps the researcher to gain rich knowledge and insight about the participants (Baumgartner and Strong, 1994; Miles and Huberman, 1994; Brink, 2002; Bless et al., 2006).

In order to explore issues in detail, qualitative research asks questions such "why and "how". These questions allow respondents to describe their experiences in detail. The questions are mostly open-ended and they allow the participants to respond in their own words. The researcher has the opportunity to probe a subject's explanations. The response to questions is spontaneous and this requires the researcher to be flexible and to adapt to the different unanticipated responses (Baumgartner and Strong, 1994; Brink, 2002).

I found it appropriate to use qualitative research methods in this study precisely because I wanted to explore and describe the experiences of caregivers. This offered me an opportunity to understand what it means to care for a child who is on ARV therapy and to learn about the challenges and coping strategies employed. In-depth interviews were used in the fieldwork and they have the advantage of being flexible and allow the researcher to capture unexpected information; to pursue answers or information that is not clear and to focus on interesting points that emerge during the interview. Interviews were conducted with primary caregivers and key informants such as nurses, social workers and counsellors in both Setswana and

English. I am from Botswana and am bilingual and I was, therefore, able to move between the two languages and pick up the nuances in both..

Quantitative Research Design

Quantitative research methodology is concerned with numerical data about the study population. The focus is on quantity and asks questions such as how much? How many? In quantitative methodology, the main source of data is the questionnaire. Obtaining data through a questionnaire has advantages. It allows the researcher to collect data from a large sample. Respondents are asked exactly the same questions. Since responses are fixed, there are no chances of unanticipated responses. The disadvantage is that people may decide not to respond to some questions and the response rate may be low. Two other limitations of using a questionnaire are, first, it is not able to capture in detail the experiences of respondents. Secondly, there is no room for respondents to give nuanced or equivocal answers (Baumgartner and Strong, 1994; Brink, 2002).

Pilot Study

A pilot study was conducted at Mahalapye Hospital before the main study commenced. This exercise provided me with an opportunity to detect any "flaws or ambiguity" in the data collection tools (Brink, 2002: 174). The pilot study also allowed me to check that the questions were clear and whether they were adequate to investigate the research question. Information gathered from a pilot may be used to improve the questionnaire. (Brink, 2002; Bless et al., 2006).

Pilot interviews were conducted with two respondents and four completed the questionnaire. Convenience sampling was used to select the participants. The pilot was conducted by the researcher. The data collection tools were found to generate the necessary information. Respondents did not show any difficulties in understanding the questions except for the one on household income. When responding to this question, mostly participants reported no income because they were not working. They did not take into consideration other sources of income such as pension grants and income from working members of the family. This made me realise that I should always clarify what the question is seeking when conducting the main study. I amended the problematic question in the main study. The pilot study also helped me to estimate the average time the interview and completion of the questionnaire would take. Data collected from the pilot study was not included in the analysis of the main study.

Data Collection

A questionnaire with 14 questions was used to obtain demographic information from primary caregivers. The questionnaire consisted mostly of closed questions and a few open-ended questions. It asked about level of education, employment status, household income and the brief medical history of the child under their care. The questionnaire was written in English and Setswana.

An interview guide with four open-ended questions was used to elicit information from the caregivers. They were asked to narrate their stories on care giving, stigma and challenges that they face in the care process. They were also asked to identify what they feel could be done to support them. I used follow-up questions to clarify what the respondent was saying and to further discuss issues that were raised by the respondent. The interview guide which consisted of key questions to which I needed answers allowed me both to direct the flow of the interview and to digress if necessary.

Data collection started on the 24th April 2008 and ended on 13th May 2008. Follow up interviews in the homes of those who took part in the in-depth interviews were conducted from the 8th through the 14th July 2008. Visits to the homes gave me an opportunity to see the conditions in which people lived and therefore served as a form of observation, something that I could not detect during interviews at the hospital. The visits also afforded me the opportunity to clarify certain issues from the previous interview and in some instances ask further questions.

I conducted individual interviews at Mahalapye hospital treatment centre. I was able to secure a room where interviews were conducted in private. I was quite aware of the fact that conducting interviews at the hospital could jeopardize people's freedom of choice on whether to participate or not. This was compounded by the fact that nurses identified caregivers and referred them to me. As a result, I reassured respondents that participation in the study was voluntary and that refusal to participate would not jeopardize their treatment. Interviews were conducted while the caregivers were still waiting in the queue to see the doctor. Most were completed before the respondent saw the doctor. Some returned to complete or start the interview after seeing the doctor. There was only one caregiver who declined to be interviewed after being seen by the doctor because she was in a hurry to go home.

The interviews were all conducted in Setswana with primary caregivers. Interviews with secondary caregivers used a combination of Setswana and English. Interviews were tape recorded with the permission of the respondents. The duration of the interview was approximately 45-60 minutes. The recorded interviews were later transcribed into interview transcripts. As mentioned above I am bilingual, so translation did not pose any problems. Transcribing interviews was a time consuming and daunting task. It involved going back and forth in order to ensure the respondents' perspectives were correctly reflected. Through transcribing, I became familiar with the stories of the respondents and the issues they were grappling with in the care process.

Data Collection Process

As mentioned earlier I relied on the nurses at the ARV clinic to identify caregivers. The nurses referred all the people who accompanied children to the room where I was conducting interviews. I then introduced myself to the caregiver and explained the purpose of the study, and emphasized the issue of voluntary participation and anonymity. I then asked the caregiver if s/he would like to take part in the study and explained that this consisted of a questionnaire and an interview. Caregivers who agreed to take part in the study were requested to sign a consent form, which was read to them and clearly explained. The questionnaire was assigned a number and that same number was written on the consent form which had the name of the participant. The participant was then asked to complete the questionnaire unless I administered it. After completing the questionnaire, which took about 20 minutes, I would ask the caregiver if s/he was willing to give an in-depth interview.

Only three prospective interviewees declined to be interviewed. One respondent discontinued her participation in the middle of the in-depth interview. One refused because she did not have time and the other two did not share the reason why they declined to take part or stopped participating. The fact that three potential respondents declined to participate should be taken as evidence that the potential interviewees did not feel intimidated or fearful of consequences if they did not participate.

Quantitative Data Analysis

Quantitative data was analyzed using descriptive statistical procedures such as percentages, frequencies and cross tabulations. This method was used to collect the socio-demographic information about primary caregivers. It was beneficial to collect socio-demographic data

because it gave an indication of who the caregivers were. The data collected was on household income, age, employment status, relationship to the child and level of education. These variables were important for this study. For example, the household income would indicate the ability or not of the carer to meet the needs of the family such as food, shelter, and treatment-related costs. The level of education was important because somebody with little or no education may have had difficulties in understanding the care process and giving the pills at the right time. The age of the caregiver would indicate if children are taken care of by elderly or young people. The relationship to the child helped to determine if children are taken care of by their parents, relatives or non-relatives.

Qualitative Data Analysis

The first step in analyzing qualitative data is to be familiar with it. This was done by reading the transcripts repeatedly. The tape recordings were also played several times. While reading data or listening to tapes, I began to identify emerging similarities and differences. I used marks to highlight similar trends or phrases that had similar meaning. Similar trends were given codes to help organize the data into categories. This was followed by placing data with similar meaning together so that themes or patterns could be identified. I continued to form categories until no new themes emerged. Following categorization, I tried to attach meaning to the grouped data by identifying similarities and differences in responses. Contradictory responses were captured and are presented in the findings. For example, only one person out of nine reported experiences of stigma while the others said there was no stigma. Both responses are reflected in the findings. The last step was to interpret the themes and in that way describe the experiences of caregivers of children who are on ARV therapy.

Ethical Considerations

Before commencing the study I approached the Ministry of Health in Botswana through the Health Research Unit to ask for ethical clearance for this study. To obtain the approval of the Ministry, I was requested to submit a research application form and a copy of the proposal, interview guide and consent form. The Health Research Unit suggested some changes in my proposal such as objectives and statement of the problem. After approval from the Ministry, I wrote a letter to the authorities at Mahalapye Hospital asking for permission to conduct interviews. After being granted permission by the hospital, I was introduced to the ARV clinic staff and finally I was able to start holding the interviews. The basic ethical principles

such as anonymity, voluntary participation, respect for persons and non-maleficence were observed during the course of the study. No children were interviewed. Older children who were with their caregivers at the hospital were asked to wait in the waiting room while the caregiver was being interviewed. Children less than five years were with their caregivers during the interviews.

Autonomy

This principle "incorporates the freedom of individual's action and choices to decide whether or not to participate in the study" (Bless, et al., 2006: 142). Important values underpinning the principle of autonomy are voluntary participation and informed consent of participants. Participation in this study was voluntary. The nature and scope of the study was verbally explained to potential respondents and this was also captured in the consent form. This helped potential respondents to make an informed decision about whether or not to participate in the study. Potential respondents were assured that refusal to participate would not jeopardise their future care needs. After these explanations caregivers who agreed to take part in the study were requested to sign a consent form. The fact that three out of 57 decided to withdraw suggests that potential respondents felt no pressure to participate.

Anonymity

Anonymity was ensured in that data was managed in such a way that the identities of participants were protected. The name of the participant or any other characteristics that could be linked to her/him was not used in the study. Participants were given pseudonyms to ensure privacy. Transcripts and questionnaires were assigned numbers for identification. Transcripts and tapes were kept in a secure place where they could only be accessed by the researcher.

Non-Maleficence

This ethical principle ensures that participants are not exposed to any harm by virtue of taking part in the study. Since HIV/AIDS is a sensitive issue, sharing experiences could evoke painful memories and this might lead to emotional distress. During the process of data collection, I encouraged the respondents to raise any discomfort that they were experiencing during the course of the interview. The respondents were informed that if they showed signs of emotional distress the interview would be stopped to allow the respondent to recover. Prior to interviews, the researcher had arranged with counsellors for possible referral of

participants who showed emotional distress. This option was not exercised because all but one of the caregivers was comfortable in sharing her/his experiences. As discussed above there was only one instance where the care giver, who was the mother of the child, decided to discontinue her participation in the middle of the interview. Her wish was honoured. The part of the interview that was recorded was destroyed and was not used in data analysis. She was offered an opportunity to see the counsellor but she declined. Respondents were not pressurized to provide information if they were not willing to do so. As such, the participants wish not to respond to certain questions was respected.

Justice

The principle of justice is based on the premise that all people have the right to fair and equal treatment when they participate in a study. To ensure this, participants were given the same information on the nature of the study and they were given equal opportunities to ask questions or raise any concerns about the study or parts of it.

Conclusion

This chapter has discussed the process that was followed to conduct the study. The study used mixed qualitative and quantitative research methods to investigate the experiences of caregivers of children who are on ARV therapy. Combining the two methods was important in corroborating the information. While the quantitative analysis was able to gather numerical data on sample characteristics, the qualitative interviews allowed the respondents' experiences and feelings to be explored in depth.

At the end of the study period, I had conducted nine in-depth interviews and forty-nine people had completed questionnaires on their socio-economic situation. This information provided me with insights into the situation of caregivers of children taking ARVs in Mahalapye.

CHAPTER 6

STUDY FINDINGS

A total of forty nine primary caregivers took part in the study. Five primary caregivers and four secondary caregivers participated in the in-depth interviews. The participants were selected purposefully. In selecting participants, I targeted both men and women. I also ensured that the participants selected came from different villages in the sub-district, rather than all coming from the same village.

Table 1: Socio-Demographic Characteristics of respondents at Mahalapye Hospital

Sex	N	%
Female	47	96%
Male	2	4%
Marital Status		
Single	37	76%
Married	7	14%
Divorced	1	2%
Widower	4	8%
Age		
15- 19	1	2%
20 – 29	11	22%
30- 39	18	37%
40- 49	10	20%
50- 59	5	10%
60+	4	8%
Education Level		
None	9	18%
Primary	19	39%
Secondary	21	43%
Tertiary	0	0%
Relation to Child		
Mother	26	51%
Father	2	4%
Grandmother	11	23%
Others	10	22%
Employment Status		
Employed	5	10%
Unemployed	44	90%
Monthly Income in Botswana Pula		
< 300		
301- 500	27	55%
501- 1000	11	22%
1001- 1500	3	6%
1501+	7	14%
	1	2%
Treatment Centre Distance (kilometres)		
<20	22	49%
21- 40	14	24%
41+	13	27%

Table 1 depicts the socio-demographic characteristics of the study sample. It is evident that the caregivers were primarily made up of women (47 out of 49); only two men were interviewed. The majority of the caregivers were in the 30-39 age group with an average age of 38 years. The oldest caregiver was a grandmother of 83 and the youngest was an 18 year old sister. Out of the 49 participants, only 7 were married while 37 were single and 4 were widowed.

Table 2: Employment Status and Gender of the Caregiver

Employed	All	Female	Male
Yes	5	4	1
No	44	43	1
Total	49	47	2

**1.00 Pula is equivalent to 1.19 South African Rand (4th May 2009).*

As can be seen in Table 2, the majority of caregivers (44 out of 49) were unemployed and only five were employed. Of the two men who took part, one was employed and the other unemployed. Out of 47 women who participated, 43 were unemployed.

Table 3: Age and Gender of the Caregiver

AGE AND GENDER				
Age	%	All	Female	Male
15-19	2%	1	1	0
20-29	22%	11	11	0
30-39	37%	18	17	1
40-49	20%	10	9	1
50-59	10%	5	5	0
60 +	8%	4	4	0
Total	100%	49	47	2

* Average age of the caregivers was 38.

Table 3 above shows the age and gender distribution of caregivers. As indicated earlier, most of the caregivers were women

Twenty one of the caregivers had secondary education while 19 had primary education. Only nine participants had no formal education and they were aged 45 years and over. Most of the caregivers (44) were unemployed. The mother was the main primary caregiver (25) followed by grandmothers (11). The other caregivers included sisters, fathers and aunts. Data shows that there were no children who were cared for by non-relatives.

Forty Six of the caregivers had been taking care of the child who was on ARV therapy for more than three years. Most of the children were of school going age. The average age of the child was 9.5 years. One of the caregivers had two children aged 13 and 15 years who were on ARV therapy. Of the 49 caregivers who were interviewed, 27 had three or more children in their care. One caregiver was taking care of nine children who were under the age of 18 years.

Table 4: Household Income and Relation to child

Household Monthly Income in Botswana Pula	Relation to Child			
	Biological Parent	Grandmother	Others	Total
< 300	14	7	6	27
301 – 500	6	3	2	11
501 – 1000	2	1	0	3
1001 – 1500	5	0	2	7
< 1500	1	0	0	1

More than half of the families were living on a monthly income of less than P300.00 Only one caregiver had an income of more than P1, 500.00 (Table 1 & 4). In households where the caregiver or any member of the family was aged 65 years and over, the old age pension of P220.00 per month was the main source of income. There were eleven grandmothers who were taking care of orphans but only one was receiving the old age pension. The other grandmothers were below the age of sixty five. Eight were staying with older relatives who were receiving the old age pension. Five other caregivers were receiving a monthly destitute food ration from the Department of Social Services.

Twenty-one out of forty nine respondents relied on government orphan care rations which in most cases was not enough for the whole family. The orphan food ration is a monthly basket of basic staples for a household with a registered orphan. Support also includes education expenses such as school fees, associated clothing and supplies. This benefit covers orphaned

children up to the age of 18 years. Respondents reported that they were supplementing household income by selling traditional beer, doing casual work, small scale farming and petty trading.

Twenty-two caregivers who took part in the study travelled less than 20 kilometres to the health facility. Most of these caregivers live in Mahalapye Village where the treatment centre is located. They spend less than P10.00 per journey to and from the treatment centre. Thirteen caregivers lived more than 41 kilometres from the treatment centre with the furthest travelling 120 kilometres. More than half of the caregivers lived more than 20km or more from the hospital.

Conclusions that can be drawn from this data are firstly, the bulk of care is provided by women; mothers and grandmothers. Income poverty was very high amongst caregivers and this could be attributed to high levels of unemployment. Most of the households survived on less than P300.00 a month, which is far below the international poverty datum line of US\$1 per day. Low household income had serious implications such as food shortages and lack of money to meet the basic needs of the family. In addition, many caregivers took care of several children in the household.

Profile of Primary Caregivers

This section will present a brief background of the five primary care gives who took part in the in-depth interviews. Visiting participants in their homes helped me to gain insight into the lives of respondents. Pseudonyms are used to identify the five caregivers. Where the HIV status of the respondent is indicated, it was based on voluntarily disclosure.

Respondent 1: "James"

James is a 38 year old man who lives in Mahalapye itself (population 44 000 people). I first met James on the 8th May 2008 at Mahalapye hospital when he had accompanied two of his three children who are on ARV therapy. I also had the opportunity to visit him at home on the 14th July 2008.

James is married and has three children aged 12, 13 and 15 years old. Two of his children are from a previous relationship and their mother passed away in 2005 because of AIDS related diseases. The children are at primary school. James's wife does not live in Mahalapye

because she works for a poultry farm about 180 kilometres away, but she does visit the family regularly.

James had completed secondary education and works for a distribution company. He had been working for this company since 1990 and earns P2, 500 per month, which is about R3, 001. His wife earns P1, 500 per month and this brings the monthly household income to P4, 000 or R4, 802.

The family lives in a three-roomed house. They do not have running water in the house but have a water tap in the yard. The house has electricity and they have electrical appliances such as a television, refrigerator and radio. The house has basic furniture such as chairs, beds, a gas stove, and table. The house does not have a flush toilet but they have a pit latrine. James has a car, but during the visit, he had taken it to the garage for repairs.

James stated that he tested HIV positive in 2005 after the death of his girlfriend. He is not yet on ARV therapy because his CD4 count is above 200. He regularly goes for check ups and the last one was on 13th March 2008. His CD4 count on this occasion was 451 compared to 403 in the previous check up. He also disclosed that his wife is HIV positive and is on ARV therapy.

The older two children of 13 and 15 are on ARV treatment. The children started treatment in 2002 and 2003 respectively. They take their medications at 6:00 and 18:00 every day. James indicated that his employer is accommodating to his requests for time to take the children to medical appointments as long as he gives at least a week's notice. The majority of the time he watches the children taking the treatment. There are times when he is unable to watch so he checks by counting the pills on a periodic basis.

He stated that he receives a lot of support from his sister who also lives in Mahalapye and she takes care of the children when he is away on official duties. He has also secured the services of a domestic helper who comes on weekends to clean the house and do laundry. During the interview, it was evident that James was comfortable discussing the HIV status of his family.

Respondent 2 "Mumpsy"

Mumpsy is a 60 year old single mother who lives in Makwate Village. In 2001, the population of Makwate was 1,591. It is about 55 kilometres east of Mahalapye Village. I met Mumpsy on the 30th April 2008 at Mahalapye Hospital when she had accompanied one of her grandchildren to the ARV clinic. A follow up visit to her home was made on the 10th July 2008.

Mumpsy had two daughters. One daughter died in 2005 from HIV/AIDS related diseases. Mumpsy's other daughter works on the commercial farms, which are far away from the village. Mumpsy lives with three grandchildren aged three, seven and twelve years old. The seven and twelve year old attend school at the local primary school.

Mumpsy did not go to school and is not working. Mumpsy is not yet eligible for a pension because she is under 65 years. The only source of income is P200.00 she is given by her daughter from time to time. She stated that she depended on the food rations issued by the Department of Social Services. She has ten goats and milks them for household use. Mumpsy lives in a one roomed cement house with little furniture. There is a mud hut in the yard and it is mainly used as a cooking area. She mainly uses an open fire for cooking. There is no toilet in the household and she stated that they use the nearby bush. The family gets water from a public standpipe, which is about 120 meters from their home. Even though there is electricity in the village, Mumpsy's house does not have electricity connected. The village has telephone services but Mumpsy does not have any access because she cannot afford it. Makwate has a daily bus service to Mahalapye. The bus fare is P10.00 each direction.

The youngest of Mumpsy's grandchildren – the three years old - is on ARV treatment. According to the grandmother, the child started treatment in 2006. She stated that the health of the child had improved greatly after starting treatment. The child takes medications at 08:00 and 20:00. The older grandchildren normally remind her to give the child medications.

The grandmother stated that she does not get any support from her relatives except a distant cousin. The grandmother looked frail and emaciated. The grandchild who is on ARV medication was well fed and bathed. She had a healthy appearance.

Respondent 3 "Thato"

My first meeting with Thato was on the 5th May 2008 at Mahalapye Hospital and the follow-up visit at her home on the 9th July 2008. Thato is a 44 year old single woman with children ranging in age from four months to 19 years. Thato is from Radisele Village, which is 40 kilometres north of Mahalapye along the A1 highway. The population of Radisele in the 2001 census was 2,741. Radisele has a primary and secondary school and a clinic with a maternity wing. Six children live with Thato. Besides her own children Thato also cares for a grandchild who is 15 months old and two of her late sister's children.

In June 2007, Thato's sister died due to HIV/AIDS, leaving behind seven children. Currently, Thato is taking care of three of her late sister's children of whom the youngest (ten years) is on ARV therapy. The child started treatment in 2007. The child takes medications at 06:00 and 18:00 every day. She uses a cell phone to remind her to give the child medications.

Thato voluntarily disclosed that she tested HIV positive in 2006, but she is not taking ARV therapy because her CD4 count is still high. Thato and the seven children live in a three-roomed house. The accommodation is not enough for the entire family and she intends to build mud houses to alleviate the situation. The house does not have running water and they collect water from a public stand pipe which is about 20 meters from their home. Electricity is available in the village, but Thato cannot afford to connect it to their house. The house has basic furniture such as chairs and beds that had belonged to her late sister. There is a pit latrine in the yard.

Thato has only completed primary education and neither she nor any members of the family are working. They rely heavily on the food ration issued to the two orphans she is taking care of. The other orphan is above the age of eighteen years and is not eligible for the orphan food ration because it is only given to orphans who are under the age of eighteen years.

Since Radisele is along the A1 highway, there is regular transport to Mahalapye village. The trip to Mahalapye costs her P5.50 each direction but she struggles to raise the money to pay the fare. This, according to her, has dragged her into debt because she is forced to borrow money every time she takes the child for medical reviews.

Respondent 4: "Keletso"

The first meeting with Keletso was on the 5th May 2008 and a follow up visit at her home was made on 8th July 2008.

Keletso is a 51 year old woman from Mmutlane Village which is 25 kilometres west of Mahalapye. According to the 2001 census, the population of the village was 841. The road to Mmutlane is currently under construction and there are no transport services. People rely on private cars to go to Mahalapye and a single journey costs P8.00. There are no telephone services or electricity in the village. The village has a primary school and a health post.

Keletso is a married mother of five children of whom one died in 2004 due to HIV/AIDS. She has two grandchildren aged six and ten years old who attend a local primary school. Keletso has primary education and has never worked in paid employment. She has one son who is working in Gaborone but does not know where he works. No other person in the family is working. Keletso's husband is a pensioner and receives a pension of P220.00 per month. They also depend on the orphan food ration for the grandchild. In addition, they plough on a small scale. Keletso's husband is on hypertensive treatment and had a stroke in 2007 that left him paralyzed on the right side of the body. The husband collects treatment at Mahalapye Hospital every month. Keletso is taking care of her ten year old grandchild who started ARV therapy in 2007. The child takes medications at 07:00 and 19:00. She relies on the radio for the time to give the child medications.

There are two mud huts in the household and there is a three roomed house that is under construction. They do not have water but get it from a neighbour. There is a pit latrine in the compound. The family uses an open fire for cooking.

Respondent 5: "Kitso"

Kitso is a 46 year old man from Mookane Village which is about 60 kilometres southeast of Mahalapye. In 2001, Mookane had a population of 2,297 (CSO, 2001). There is no transport service between Mahalapye and Mookane Village and people depend on private vehicles. The fare to Mahalapye is P15.00 per journey. The village has a clinic with a maternity wing, a primary school and a secondary school. The clinic does not offer ARV therapy, so people have to travel to Mahalapye.

I met Kitso on the 6th May 2008 at Mahalapye Hospital and held a follow-up meeting on the 11th July 2008. Kitso is single and has a ten year old child who started ARV therapy in 2007. He disclosed that he was also on ARV treatment. The mother of the child died in 2002 due to HIV/AIDS related causes. The child spends most of her time with her father and paternal grandmother. During the follow-up visit on 11th July 2008, I was informed that she had gone to live with an in Gaborone.

Kitso stays with his parents who are both receiving the old age pension of P220.00 per month each. There are nine people on the compound of whom three are children under five years. Household income is supplemented by farming on their plot, temporary jobs in the building industry and occasional work with livestock.

There are two huts in the compound and a two roomed cement house. Cooking is done on the open fire. They get water from a public standpipe which is less than 20 metres away.

Emerging Themes from Primary Caregivers

Seven themes emerged from the analysis of interview transcripts that described the experiences of caregivers of children who are on ARV therapy.

Theme 1: Monitoring the Child's Treatment

Caregivers were asked to describe what it was like to care for a child who is taking ARV therapy. All the caregivers indicated that they have to monitor the child's treatment. The sub-themes under this theme were; administration of medications and accompanying the child for medical reviews.

All the caregivers interviewed gave the child/ren in their care the medications as prescribed by the doctor. Kitso had this to say about the issue.

"The child is taking medications regularly. I give her medications daily. I give her treatment at 07:00 and 19:00."

Thato shared the same sentiments.

"I am giving the child treatment as prescribed. I make sure that the child takes treatment in the morning and evening every day."

Caregivers use different strategies as reminders to give treatment on time. Some use watches, cell phones, news on the radio and some are reminded by older children in the household as evidenced by the following comment by "Mumpsy".

"My cousin has bought me a watch to use, but I can't read. I do not know how to use it. My older grandchild is the one who reminds me when to give the child medications."

When asked if the children under their care had ever missed taking their medications, all caregivers reported that it had never happened. This is contrary to what was reported by secondary caregivers.

The interviews revealed that the child should come to the hospital for medical review on a monthly basis. Children are normally given a month's supply of treatment. James had this to say.

"I am the one who collects their drugs from the hospital. If it is time to see the Doctor, I bring them."

Thato echoed the same sentiments.

"I also have to bring the child to the hospital for check-ups. I have to observe if he is not well. If the child is not well I take him to the hospital or clinic."

Caregivers stated that children under their care had never missed medical appointments. Those who cannot read devised strategies of knowing when to take the child to the hospital such as reminders by other family members or seeking help from the local health facility;

"The child has never missed going to see the doctor. My older grandchild reminds me of the date the child should see the doctor. At times, I take the medical cards and go to the health post and ask them when the child should go to Mahalapye Hospital (Mumpsy, primary caregiver)."

However, it was also evident from the interviews that some children had in the past missed medical appointments. Three caregivers talked about missed appointments in the past. When asked if the child had ever missed appointments Kitso said:

"No. It is only yesterday, I was not around. The child should have come for review yesterday, but there was nobody to bring her to the hospital. My mother was going for a check-up at Mookane Clinic, so, she couldn't bring her to Mahalapye Hospital.

The above extract shows the disadvantage of not having facilities that offer integrated services. If Mookane clinic was offering ARV services the grandmother could have taken the child with her.

Theme 2: Health of the Child

The results show that before the children started ARV therapy they were frequently sick from ailments such as diarrhoea, a persistent cough, skin infections, stunted growth and repeated admissions to the hospital. Keletso asserted that:

"The child was not well. The child had frequent diarrhoea and was under weight and always coughing. The child was treated for tuberculosis."

James, who has two children who are on ARV therapy, shared these views.

"The children were not well. My younger child was sick very often, he was sick most of the time and I couldn't work properly."

The excerpts show that children had poor health because of their compromised immunity and this affected their growth and development. This also affected their schooling with some children left far behind their age mates.

All the caregivers indicated that since the children started treatment their health had improved tremendously. There was only one caregiver who at the time of the interview indicated that the child was not well. She explained that:

"Since starting treatment he has improved. He wouldn't be alive if it was not for ARVs. Right now the child is not well. While taking treatment (ARV) he was also taking TB treatment and it was stopped in February. He was responding well. Right now he is losing weight. I am wondering what the problem is because we are not short of food at home. I suspect that something is wrong. (Thato is a caregiver of a 10 year old child)."

The excerpts show that the children are responding to treatment and are in greatly improved health since starting treatment. This is a source of motivation to the caregivers. It also shows that even though they are on ARV therapy, children can still fall sick. The interviews revealed that the respondents were satisfied with the effect of ARV treatment on the health of the children. This has encouraged them to observe the treatment schedules.

Theme 3: Disclosure of Child's HIV Status

Disclosure of the child's HIV status was a common experience amongst caregivers. The results show two types of disclosure; i.e. internal and external disclosure. Internal disclosure is when the child and family members have been told the HIV status of the child. External disclosure is when the HIV status has been disclosed to people outside the family such as teachers and pastors.

Internal Disclosure

All five caregivers interviewed indicated that they had disclosed to close family members such as the grandparents and the older siblings. Disclosure to the family member is selective. The principal caregivers often confide in people they trust and those who could supervise treatment in their absence. Kitso had this to say about internal disclosure:

Only my mother and sister know the HIV status of the child. They know that she is taking ARV. They are the ones who help in caring for the child. I did not tell other family members because I feared that they may discriminate her

The other caregiver had this to say:

Only the older children know that the child is taking ARV. Other members of the family know that the child is taking tablets every morning and evening but they do not know that it is ARV (Thato, secondary caregiver).

External Disclosure

The interviews also showed that external disclosure was also done selectively. . In most cases external disclosure is based on the perceived support the caregiver could receive after that. Four out of the five primary caregivers who were interviewed had disclosed to the school. The reason for so doing was based on the potential benefits for the child. James, the father of two children on ARV therapy, had this to say on external disclosure:

"I did tell them (the school) the status of the children, so that they should know the kind of persons they have in their class and that I will regularly come and ask permission to take them to the doctor. I didn't want them to be surprised. I frequently come to ask for permission to take the children. I told them because I wanted their support for the children. I told them that the children can be punished like any other child, but they should know that they are sick. If they have a problem like bleeding they will know how to handle them."

When asked why she disclosed the child's status to the teachers Keletso stated that:

"It was because the child was taking the medications late. So the teacher suggested that since the child leaves home early in the morning, I should give him the drugs so that the child could take the morning dose at school. The teacher had said that he will make sure that the child takes medications."

KM: *"So the child takes the morning dose at school?"*

Keletso: *"Yes. The child is taking the morning dose at school under the supervision of the teacher."*

Kitso shared the same sentiments:

"I have told the class teacher that the child is taking ARV. I told the class teacher because I was always asking for permission to take the child to the hospital. I did not want the class teacher to be surprised when I come to ask for permission to take the child to the hospital".

Disclosure to the child

Most of the children had not been told their HIV status. Reasons given for not disclosing to the child were that the child was still young. Some caregivers stated that they did not want to frighten the child, while some said they don't know how to disclose to the child. As a result, most children did not know why they were taking the medication. In most cases children had only been told that they are sick and they should take medications. Responding to the question of disclosure the following conversation between the researcher and respondents explains the issue of disclosure to the child.

KM: *"Does the child know why she is taking these medications?"*

Kitso: *"I don't know if she understands why she is taking these drugs."*

KM: *"Have you told her?"*

Kitso: *"No. I haven't told her, but she knows the times of taking treatment, even the doctor's appointment dates."*

Thato, a caregiver of a 10 year old child had this to say about the issue of disclosure to the child.

KM: *"Does the child understand why he is taking this treatment?"*

Thato: *"I have tried to tell him why he is taking these drugs. I am teaching him gradually why he is taking these drugs. He is still young and has even said that when he grows up he is going to stop taking these drugs. But I keep telling him that he is going to take this treatment for the rest of his life. He asked me why he should be taking treatment for the rest of his life. I have explained to him that when his mother was pregnant the disease passed to him. So you will take treatment for the rest of your life."*

Responding to the question of disclosure to the child James had this to say:

My children know why they are taking treatment. I sat them down and explained everything to them. I have been giving them information appropriate to their age but now they are 13 and 15 years old and they understand why they are taking treatment.

Three of the five caregivers who participated in the in-depth interview indicated that the children do not know their diagnosis. Caregivers expressed the view that it was inappropriate to tell a young child their HIV status. In most cases children were just told that they are sick and as a result should take treatment

Theme 4: Financial Constraints / Poverty

Financial constraint was an overwhelming concern that was raised by caregivers. Three sub-themes emerged and these were; lack of consistent income, transport costs and insufficient food. The quantitative and qualitative data showed that most caregivers did not have a regular source of income, and this was one of the major challenges they faced. Most of the caregivers

were unemployed and other family members were not engaged in any income generating activity. Lack of a regular income had led to financial insecurity in most of the households. This had in turn affected the caregiver's ability to meet the basic needs of the sick child and other family members. Caregivers were asked about the kind of support that they needed. Without exception they all indicated the need for financial support to be able to meet the material needs of the family. That explains that:

“My problems.... I am poor so if food ration could be stopped I would have problems. I am not working and I cannot go anywhere because there is nobody to leave the child with to look for a job. The child is still young. Even if there was a job advert in Mahalapye (which is 40 kilometres away), there is nobody to leave the child with to look for a job. The child is under my care, it is I who has to make sure that he takes medications. I have problems because there is nothing I can do.”

Mumpsy, the 60 year old caring for a three year old child who is on ARV and two other children stated that:

“I can't work, I am the only one left with the child. What kind of work can I do? I cannot find work from the white farmers with such a small child. There should be somebody to remain behind taking care of the child.”

The above extracts show that caring for a sick child restricts the caregiver from looking for a paid job outside the household. Caregivers stated that they were constrained because there was nobody to take care of the child in their absence. The restrictions imposed on their own lives because of their role as caregivers frustrated some caregivers. Others felt isolated by the extended family.

Results also show that caregivers travel from various places to access treatment at Mahalapye Hospital. All the villages where participants live have a health facility, but unfortunately, they do not provide the ARV programme. Treatment is currently only accessible at Mahalapye Hospital, which is the nearest site. Two scenarios emerged from the results; being unable to take transport to the hospital because there was none or lacking the money to pay for transport. Some areas do not have public transport and people rely on private vehicles while those living alongside the A1 highway have more accessibility to transport. Some caregivers travel long distances on a monthly basis to receive treatment in Mahalapye and this is a

challenge. The background of caregivers has shown that the highest fare to the treatment centre was P15.00 one way. Although this may seem a small amount, it is a challenge for many people who live under conditions of extreme poverty. Failure to raise the money for the fare normally means that appointments are missed. The following narrative demonstrates the plight and association of transport and poverty.

“I have had difficulties to bring the child to the hospital. Actually, I had to borrow money to be able to come here today. I don’t know if the older siblings will help me pay back the money or not (Thato, caregiver of a ten year old niece).”

This thought was also reflected by Keletso:

“The problem that I am faced with is money for transport to come here. Transport money every month. There is need for money. I do not have money. I do struggle to get here. I have to beg and ask for help from other people.”

Both primary caregivers and health workers concur that transportation to a centrally located treatment site is a challenge. This is compounded by the low socio-economic status of caregivers. As most of them stated, they are in debt because they are continually borrowing money which they are not able to pay back.

Shortage of food was mentioned by four of the respondents. Only one caregiver did not have problems with food because he had a full time job. Caregivers indicated that they have to give treatment after meals but there are times they have to give treatment to hungry children. Households that receive orphan care rations have an advantage of some food supplement on a monthly basis over those who are not enrolled in the orphan care programme. But the food rations finish quickly because most households have many people who were not working and who also depend on the ration. One caregiver explained the food situation in the following way:

“I wish I could be helped with food, because at times there is no food. The child should eat before taking medications. If there is no food and it is time to take treatment, I give her drugs on an empty stomach.”

One caregiver, who is given a food ration for the orphan had this to say:

"We are helped by the food ration. However, when the ration is finished, I struggle to find food. I end up brewing traditional beer to sell and use the proceeds to supplement the food ration (Keletso, a primary caregiver)."

Theme 5: Social and Psychological Support

The results show that while some caregivers were receiving support from family members, some were shouldering the responsibility alone. Three out of the five participants felt that the extended family was not helping and they often felt alone and isolated. Where support was available it was in the form of money for transport, taking care of the child in the absence of the caregiver and giving medications and taking the child to the hospital for medical review. Even though some speculated that it could be due to the fact that they have not disclosed, they maintained that the relatives know that they are taking care of a sick child. Mumpsy explained the issue of family support:

"There is only one person who is helping me. She is a distant cousin. Only one person, she is the only person. She is the only person whom I can go to and ask for money. Whenever I go to her, she always gives me money for transport to the hospital. She doesn't want me to pay back. She is the only one who helps me. All the others are not helping."

Thato also indicated that she was not getting any support from her family. Even though she wanted to look for a job, there is nobody who could in the meantime look after the child. This is despite the fact that there are aunts and uncles close by but they were not willing to help.

The results have shown that caregivers use the hospital as their main support system. At the hospital, caregivers and children are counselled on adherence and for any emerging problems during the course of care giving. It was evident when interviewing health workers that the emphasis of counselling tends to focus on the caregiver with little focus on the child. Mpho, a secondary caregiver, explained

"What happens is that children come with caregivers, primary caregivers of course. Then what happens is that the focus is on primary caregivers. Children are neglected."

KM: *"Regardless of the age of the child."*

Mpho: *"Regardless of the age of the child, the child will be there, but just playing. This results in the child not knowing anything. We focus on the caregivers; children do not know why they are there. They don't understand why they are seen by the doctor. The main focus is on the caregiver."*

This assertion was affirmed by another health worker who stated that:

"Before the child starts treatment, there is what we call group adherence counselling. Counselling that is done in the hospital. That is where we meet caregivers and children. But, the way it is, it focuses more on caregivers. You see, it is like that. Whether the child is there or not, whether the child is listening or not, it is like we are focusing the information on the care giver (Kentse, secondary caregiver)."

The lack of focus on the child may explain why most of the children did not know why they were frequenting the hospital and why they were taking medications.

The other source of support is from the Department of Social Services, where those who care for orphans are assisted with monthly food rations and educational needs. The department also handles referrals from the hospital of caregivers who are poor and struggling with food and financial issues.

It is not automatic that any person who is on treatment gets food. But what we do as social workers is to explain that it is only destitute people who benefit from the food basket; those who have been assessed and it is determined that they are poor. We normally explain this during adherence counselling. If there is a problem, we liaise with the Department of Social and Community Development (Kentse, secondary caregiver)."

It was evident when interviewing primary caregivers that community support through non-governmental organizations did not exist. All the caregivers indicated that they have never received any assistance from a community organization. The interviews also revealed that caregivers were not members of any support group of people living with or affected by HIV/AIDS. Four of the five caregivers who were interviewed were members of a church but they stated that they were not getting any comprehensive support from the church.

Caregivers did however identify the school as a support system. Four of the five caregivers were taking care of children who are attending school. The caregivers stated that the school was cooperating and always gives them permission to take the children for medical reviews.

Primary caregivers mentioned talking to someone as the most common method of coping with the emotional stress that is related to care giving. The second commonest was praying.

"When I feel down, I attend church. I like praying. I normally call my wife and tell her my problem. She is the person who motivates and comforts me (James, primary caregiver)."

Theme 6: Stigma and Discrimination

During interviews, four out of the five caregivers indicated that they had never experienced stigma or discrimination on the basis of the HIV status of the child. This applied at home and at community institutions like churches and schools. However, even though they did not experience stigma there was fear of it. Kitso explains why he had only disclosed the child's status to the mother and sister and not the other members of the household.

"Only my mother and sister know the status of the child. I didn't tell the other people in the household because I feared that they could discriminate the child."

James is the only one who reported that his son was stigmatized at school. In this instance, the caregiver had disclosed the status of the child to the class teacher who then told the whole class that the child was taking AIDS treatment and gave examples about the child in class. The classmates then started to scorn and ridicule his son.

"The younger one had a problem at school. The teacher and the other children were saying this one is taking treatment for such and such. When you say that, the other children are not comfortable playing with the child. They are not able to love this child. They started distancing themselves from the child. This hurt the child. My son told me this. I was really hurt. I ended up taking leave from work so that I could go and meet the Head Teacher. The situation was not nice."

James stated that he ended up removing his children from that school and now they are attending school in a different village. The current school knows the HIV status of the children but they have never experienced any stigma or discrimination. Health workers also

asserted that patients were not stigmatized. They stated that mostly people have accepted their status and have no problem in seeking help. Kentse, a secondary caregiver explains that:

"I do not see people being stigmatized. I do not know...maybe when people come to the hospital they have already taken a decision to get help. Even if people default from treatment, it is not associated with stigma. It is mostly associated with poverty."

Theme 7: Health of Other Household Members

Throughout the interviews, a recurrent issue was the health of the care giver and other household members and the impact on care giving. The qualitative and quantitative data corroborated the fact that most caregivers were themselves HIV positive. Out of the five caregivers who were interviewed three reported that they were living with HIV although only one was on ARV therapy. The two caregivers who were not on treatment had to regularly go for CD4 count testing. The two caregivers, who stated their CD4 count, said it was slightly above 400. It was evident from the interviews that the HIV positive status of a caregiver played a major role in deciding to access ARV for the children. This, coupled with accompanying the child to the treatment centre may put a lot of pressure; either financially or emotionally on the caregiver.

KM: *"How did you feel when you were told that the child was HIV positive?"*

Kitso: *"You know what, I decided to bring the child in for testing because I had also tested HIV positive myself. So, I found it necessary to take her for ARV therapy."*

James expressed the following views when asked how he felt when he was told that his two sons were HIV positive:

"I had already accepted the situation. I had told myself that I would accept any outcome of the test. I was hurting because they did not tell me her (the children's mother) status and she ended up dying. She was afraid to tell me that she had tested positive, but she could have told me. I could have encouraged her to join programmes. My wife is also living with HIV, I am also living with HIV but I haven't started ARV therapy because my CD4 count is still high."

The above excerpts demonstrate that an HIV positive status or having had a relative with HIV can act as a motivating factor to access treatment for the child and to ensure that the child

adheres to treatment. But it also indicates the fear of rejection that a parent or partner may feel.

Visits to the families revealed that in three households some family members had other chronic diseases such as hypertension. The sick relatives collect medications at Mahalapye hospital. The dates do not correspond with the date of the HIV positive child's medical appointment and means an additional trip to the hospital. This situation exerts a lot of financial and emotional pressure on the caregiver.

Emerging Themes from Secondary Caregivers

Four secondary caregivers were interviewed of whom there was one man and three women. From their interview, four themes emerged.

Theme 1: Adherence Problems

Poor adherence to ARV therapy amongst children was a recurring theme throughout the interviews. The secondary caregivers all said that children were defaulting from treatment especially those not being taken care of by their parents. They attributed poor adherence to poverty, lack of supervision of medications by caregivers and difficulties the caregivers had in working out doses of drugs especially syrups.

"Most of these children are not taking treatment properly. Most of the defaulters we have are children, mostly those who are not living with their parents. They are staying with grandparents. Grandparents cannot read. They do not even know how to give the child 10 millilitres. It is very difficult for grandparents to measure the drug (Lesedi, Secondary Caregiver at the Hospital)."

Kentse, expressed the same views:

"You know, even if I do not have numbers now, we do see quite a number of children who are defaulting from treatment. It looks like they are not taking medications properly and some do not know why they are taking medications. We do see quite a number."

Interviews with secondary caregivers revealed that there have been situations where treatment was stopped for a short period while adherence counselling was provided for the

caregiver and other members of the family. It was also evident that there were situations where treatment was stopped completely because of poor adherence. Kentse explained that:

“Actually there are some cases where treatment was stopped for a short time while trying to intervene in the situation. This was because the child was defaulting and because of the dangers of continuing treatment under such circumstances, the doctor stops treatment and then we intervene, the child is re-started after establishing the correct support system and care giver of the child.”

Giving an example where treatment was stopped indefinitely Lesedi explained that:

“We had one child; I would say it was poor adherence. He refused to take treatment. He was 9 or 10 years old. He was staying with the grandmother. Both parents had passed away. So, when the grandmother wanted to bring him for review, he would refuse. At times, he would come and they would collect drugs but when they are at home, he would refuse to take medications. He would fight the grandparents. Social workers and other relatives were involved. We sat down with doctors to talk to him. He was referred back to social workers where he stated that he does not want to take treatment. So treatment was stopped indefinitely. It was stopped after a long process to try and encourage him to take treatment, because even other relatives apart from the grandparents were involved. They also tried to talk to him without any success.”

Several reasons were given for defaulting treatment, this included; lack of supervision by caregivers, drug related issues such as taste, financial constraints and poor health of caregivers. Mpho asserted that:

“They (children) do not understand why they are taking treatment. These drugs have fatigue, they get tired. The taste is bad for children. Children complain that they are bitter to swallow. Some state that the tablets are too big and they end up not taking them. Some, to satisfy the car givers, would take out the tablet from the container and pretend that they have taken it and they throw it away. The caregiver would think that the child is taking treatment. It would look like the child is taking treatment. When they are brought to the hospital the viral load is very high.”

The above excerpts have demonstrated the challenges caregivers face when they monitor the child's treatment. The size of the pills and the bitterness of the medicine make it very hard to

make sure that the children actually take the treatment. Anyone who has tried to encourage a child to take a pill that makes her/him gag, or swallow bitter medicine, will know how upsetting it is for both the child and the caregiver. When the pills also have to be taken on an empty stomach these problems are compounded. Why the ten year old boy refused to take treatment was not made clear. Perhaps nobody knew. It sounds as though he needed psychological support but psychological services do not exist in these villages.

While some children do honour their medical appointments, the three health workers who were interviewed concurred that there was a substantial number of children who miss appointments. Many reasons were advanced for failure to bring children such as lack of transport money, forgetfulness and negligence. One health worker said that:

"Actually it is due to lack of good care giving. You will find that sometimes when the caregiver is an older woman, she is not able to come to the hospital with the child because of age. As a result, the child may miss appointments. At times the older women cannot read what is written in the hospital cards such as the date for check-ups. It then becomes a problem. At times, after the death of the parents the family is left with the child...there is an element of negligence; there is an element of poverty. You find that all these are obstacles (Kentse secondary caregiver)."

This extract shows that children do default from treatment. This was also observed by the researcher at the hospital. There was a child who had defaulted for four months because the elderly grandmother was sick and not able to accompany the child to the hospital.

Defaulting from treatment was also cited by another secondary caregiver who stated that:

"Hey, really, defaulting among children is common. I believe that most of the time it is caused by the fact that children are staying with older people. Some children are neglected. You find that most of the detectable viral loads are in patients who are children. Most of them are young children. This is because children are not given their medications properly. Some children miss check-ups, some do not come for refill. (Lesedi; Secondary Care giver)."

It was evident from interviews and observations that some children come to see the doctor unaccompanied. I observed a number of children, some as young as twelve years, who were not accompanied. Reasons advanced for not accompanying children are many such as being

busy in the fields or having other children to take care of. Secondary caregivers admitted that under such conditions they normally attend to the child but also try to intervene in the family. In some cases such children are accompanied by the social worker when they are seen by the doctor. This is common among children whose parents have passed away and who are taken care of by distant relatives. Kentse said this:

"There is one child who was staying in Mahalapye. He used to come alone because the aunt was busy with other things. He was intelligent and he would check the doctor's appointment dates and would normally come alone. When he is in the hospital the social worker accompanies him to see the doctor. We did this while on the other hand we were intervening in the family. It was really difficult."

From the extracts on this theme, it can be deduced that there are challenges in monitoring the child's treatment. In some situations, poor adherence has led to the temporary suspension of treatment. The views of the secondary caregivers on adherence differed with those of the primary caregivers. This contradiction could be due to the fact that the secondary caregivers were looking at the bigger picture of all children who are on ARV therapy at the hospital while the caregivers interviewed for this study were those who did take the children to their appointments. Nevertheless, it is worrying that there seem to be significant numbers of children who are receiving treatment erratically. Not only does this affect their own chances of long term survival, but the possibility of drug-resistant strains of the virus emerging is very real.

Theme 2: Poverty

The health workers concurred with primary caregivers on the fact that transport to the treatment centre poses a serious challenge and that it is the main reason for failure to come for reviews. Most of the caregivers are poor and not able to raise the bus fare. Kentse expresses the following views on the issue of transport.

"Yes, that is a real challenge. It is a big challenge especially for those who live in the settlements [far away places]. Actually they do not come. When they do not come for medical appointments, the main reason is lack of transport. Normally they would wait for any vehicle that may pass there occasionally. There is no transport. They do not have money for transport. The issue is poverty. Some have even suggested that there should be mobile clinics to far away places. You can really see that these are genuine

cases. Transport is a very serious burning issue and the problem of transport is a big. The reasons are that there was not transport or there was no money because people who come here are of low socio economic status."

Theme 3: Non-Disclosure to the Child

Secondary caregivers concurred that most children have not been told their HIV status and as such do not know why they are taking treatment. Lesedi, reported that:

"Most parents do not tell the children the truth. They tell them that they are taking TB treatment. Intelligent children would then question why they are still taking treatment after six months because TB treatment takes 6-12 months. Most parents do not tell them the truth, even though we encourage them to do that."

Mpho agreed.

"You ask a child why he/she is taking treatment he would say I am sick. They don't know what they are suffering from. They just know that they are sick. They are told that they have flu and after the flu, he/she would want to stop treatment. Some children do not ask, they do not ask at all. They just continue taking drugs. When the child begins to understand that he is taking ARV, he then becomes angry, starts to ask why. Sometimes they decide to stop treatment on their own. They start being rebellious."

On why parents do not tell children their HIV status Mpho explains as follows:

"I (primary caregiver) didn't find it important. This is a child; I did not want to worry him. I do not want to tell him that he has HIV and is going to die. Some would say, they do not know what to say to the child. I could not just do it. I felt that it was better to come to you (secondary caregiver). It is a very difficult situation to address."

When asked if the primary caregivers are counselled about how to tell the child, Kentse stated that:

"Actually, the system as it is right now, we do not. What happens, as I said earlier, we go for adherence counselling then its like we wait for problems to happen, that is when we intervene such as disclosing to the child. Sometimes the caregiver (primary) will come with the child and we disclose to them.."

Lesedi, had this to say:

"During adherence counselling, I can't say we are disclosing, we are not disclosing. We encourage caregivers to disclose to the children. We encourage parents to gradually disclose to the child especially those 10 years and above. As time goes on and we realize that the child understands we encourage the caregiver to tell the child his/her status. At times parents say they cannot disclose. In that situation we refer them to the social worker."

Theme 4: Lack of Psychological Support for Health Workers

Lack of emotional support was an overwhelming concern raised by secondary caregivers. The three health workers who were interviewed agreed about the stressful nature of their job and that there were no support system in place for them. They said that the focus is on the client. When asked what they do after attending to a stressful or difficult case, whether they had a support group themselves, Mpho had this to say:

"Unfortunately [laughing] we do not do that. What we do is, hey people, I had a difficult case, I am tired, saying that to your colleagues. That is what we do. After that, we do not talk much about it. We know that some cases drain us and sometimes we end up being emotional. Unfortunately we do not have support structures in place."

Kentse said the same thing.

"That is a problem. Actually, we do not have support systems in place. We really feel that we need support as caregivers but at the end, there is nothing. We are just focusing on the client. There are those cases where you feel exhausted, even when you are asleep you dream about them. You just have to try and motivate yourself [laughing]. To tell the truth there is nothing at the moment."

Lesedi describes the stressful situation encountered:

"Ah, me, I don't know about others but myself I don't do anything. I just isolate myself and ask myself questions. Something that stresses me more is seeing young children who are some months old. We have children who are less than one year and are on treatment. So when I am in a consulting room and a young child is being

attended, it is really difficult. At times I start crying, thinking that life's such a long thing, and a child who is some months old is starting lifelong treatment. It is very stressful. You know our job is very stressful. At times when you get home and your child is trying to talk to you, you are just thinking about the problems at the work place asking yourself how the problem could be solved. But [laughing] I have never asked for help anywhere."

The above extracts have demonstrated the emotional strain experienced by health workers. It also shows that the workplace does not have programmes in place to address the needs of secondary caregivers.

Conclusion

This chapter presented the findings from the qualitative and quantitative data collected from caregivers. This was done by looking at the socio-demographic characteristics of the sample and the themes emerging from the in-depth interviews. Based on the findings, it is evident that care giving places heavy demands on caregivers. The findings demonstrate that care providers are discharging their roles under difficult conditions of resource constraints.

Household poverty was identified as the main challenge facing caregivers. Care providers experienced many forms of poverty such as low income, inadequate housing, food shortages, material deprivation and lack of basic necessities. Poverty was fuelled by high levels of unemployment, lack of skills and low education. The main source of income was the pension grant if there was an eligible person in the family. Families housing orphans relied on the orphan care ration. This demonstrates the importance of these social welfare provisions in alleviating poverty. To cope with the financial demands of care giving, most caregivers resorted to borrowing money. In most cases borrowing led to the indebtedness of households.

Most of the caregivers were biological parents and were unemployed and did not have any source of income. As a result, they lacked basic necessities. Even though school fees have been abolished, these households still had to bear the costs of purchasing the uniform. Households with orphans were found to be better off because they had a regular source of support through the orphan care programme. This included the food rations. Yet often the ration intended for the orphan had to stretch to feed the family.

Basic services such as water and electricity are provided in most of the villages, but most of the respondents did not have such services in their homes because they could not afford the charges. Households that did not have running water collected water from public standpipes. Furthermore, there was lack of basic sanitary facilities such as pit latrines. The respondents talked about the illnesses the children had before they started treatment. These included diarrhoea. It is difficult to imagine how a caregiver deals with a small child with diarrhoea when she has neither running water nor electricity.

It was evident from the findings that most households were headed by women and they tend to experience more poverty than male-headed homes. The two men who took part in the study had the highest income among the participants. Women living in these poor conditions were also burdened by the responsibility to provide for the basic needs of the household.

Results also showed the devastating impact of multiple infections within a family. In many households, caregivers are burdened by caring for more than one person with HIV. We have seen that some caregivers are themselves living with HIV and as such are grappling with their own health problems. Out of the five caregivers who took part in the in-depth interviews, three were infected with HIV. Most, but not all of the caregivers who are HIV positive, were on ARV therapy. Those who were not on therapy have to go for regular monitoring of CD4 and viral load.

A surprising finding from this study was that most of the caregivers were biological parents. Out of the 49 caregivers who participated in the study, 27 were biological parents. This is contrary to the commonly held view that grandparents are the primary caregivers in the context of HIV/AIDS. As stated earlier some caregivers were on ARV therapy and that could have helped to prolong their lives. This could also be attributed to the availability of treatment for opportunistic infectious such as TB which is the leading cause of death amongst people living with HIV/AIDS.

A consistent concern raised during interviews was the challenge of disclosing the HIV status of the child. It was evident from the interviews that most caregivers did not have the skills to disclose to the child. Even though respondents stated that they had never been stigmatized on the basis of the child's HIV status, the fear of stigma and rejection was evident during interviews.

Also evident throughout the interviews was the remarkable determination of caregivers to ensure that children under their care adhered to treatment. Financial challenges faced by many and the long distance to the treatment centre did not deter them from honouring medical appointments for the children's check ups. Stories told by the caregivers revealed their confidence in ARV therapy. They expressed profound gratitude for the positive impact ARV therapy had had on the lives of the children. This was expressed as the main motivating factor to ensure compliance with treatment.

Health workers raised a concern about the quality of care provided by grandparents. They were of the view that grandparents were not providing quality care to the children because of age. While it is true that age could constrain elderly caregivers from providing good care, the study found that most of them were not very old. Only four caregivers were over the age of 60 years. Visits to the homes showed that with all the limitations that they had grandparents were doing all they could to provide adequate care. Most of the children had good school attendance and were taking treatment as prescribed.

The findings also highlighted good school attendance by children under the care of the respondents. All children of school going age were attending school. This could be attributed to the government policy of free ten year basic education.

Respondents were able to identify the support they needed that could make a difference in the care process. There was overwhelming need for financial support to buy food, cater for transportation to the hospital and buy other household necessities.

Caring for children who are on ARV therapy also places considerable strain on secondary caregivers. Stressful situations have a potential to cause burnout, which in turn may affect the quality of care provided. This could also lead to staff turnover. Surprisingly, the study found that there were no psychosocial support systems in place for health workers.

The findings have demonstrated that there is need to strengthen the capacity of the caregivers so that they are able to protect and care for the children in their care. The findings also have implications for policy. It is to this that I now turn.

CHAPTER 7

DISCUSSION

The purpose of this Chapter is to interpret what the findings of this study reveal about caring for a child who is on ARV therapy. The findings will be discussed in relation to existing literature. This is done to determine if the findings are consistent with or contradict the results of previous studies. The discussion will be based on the themes identified in the previous chapter.

The results reveal that a typical caregiver of a child who is on ARV therapy is likely to be a woman who in most cases is single and unemployed. The high level of unemployment of care providers results in lack of income, which in turn affects the wellbeing of the family. The burden of caring is compounded by the fact that the woman may be HIV positive herself and thus has to care for herself, the infected child and carry out other domestic work. The care for the sick can also have opportunity costs for women and contributes to their impoverishment. Care provision reduces the time women can spend on income generating activities and it prevents many from seeking paid employment. This is consistent with results of other studies which have reported that the burden of care was disproportionately placed on women who in most cases live in poor economic conditions (Akintola 2004; Jacques and Stegling, 2004; Moore and Henry, 2005; Heyman, et al., 2007; Hunter, 2007).

The low involvement of men in care giving has been observed in voluntary organizations such as home based care (Moore & Henry, 2005). This has been attributed to the socio-cultural practices in which women are traditionally expected to carry out nurturing activities while men engage in activities that require physical strength. Some men are not directly involved in care giving because they are engaged in income generating activities that sustain the family (Akintola, 2004: 34; Moore and Henry, 2005). Commenting on the low involvement of men in care giving, Moore and Henry (2005:152) assert that it is "only when females in the household are not able to care for the sick that the males step in." This was evident in the current study. The two men who were interviewed indicated that the mothers of the children they were taking care of had died and as such they were the sole caregivers. However, both men, contrary to the conventional academic wisdom and popular stereotypes, cared deeply for their children. They made sure they took their pills, attended hospital appointments and went to school. Where the children of one of the men were ostracized by

the school the father removed them. This father kept in close touch with the school to ensure the wellbeing of his children. Again, contrary to popular belief, these men both expressed deep regret that their deceased wives had not disclosed their status to them.

The quantitative data also showed that most caregivers (28 out of 49) were biological parents. This could be attributed to the advent of ARV therapy, in that most parents who are HIV infected are able to live longer and thus take care of their children. This is contrary to previous studies which found that in most cases caregivers were elderly grandparents or relatives (More and Henry, 2005; Kajura et al, 2006). It is also evident that all caregivers were family members and relatives. There was no situation where a child was taken care of by somebody to whom she or he was not related. There were no children who were in foster or institutional care. Even though taking care of a child who is on ARV poses challenges it is evident that the extended family is still absorbing children and taking on care giving responsibilities, especially after the death of the parents. Most of the caregivers felt that they were obliged to take care of the children after the death of the parents. The majority of them stated that they were the only relative who could take care of the child. This is consistent with other studies which have demonstrated the role played by the extended family as a social safety net (UNAIDS, 2004; More and Henry, 2005; Hunter, 2007; Tamasane, 2009).

Most of the caregivers (40 out of 49) in this study reported some formal education with 21 having secondary education and only nine having no education. It can be inferred that the parents with more schooling may cope with the needs of providing care and be better able to understand what is required of them; if for no other reason than they can read the instructions on the pill bottles. Nevertheless, even carers who were unable to read and write made sure that they knew when the child's medicine should be taken and when hospital appointments were to take place.

Interviews with health workers revealed that primary care providers with little or no education had difficulties in understanding the treatment regimen of the children under their care. They had difficulties in giving correct doses especially if it involved syrup. This finding supports previous research that illiterate people find it difficult to follow the rigid drug protocol. Some studies have found that there was a relationship between low education and poor adherence rates. Wolf, et al., (2005) found that patients with limited education had difficulty in understanding their treatment as compared to those with high literacy. Poor

adherence due to missed doses may affect the effectiveness of the drugs and consequently cause drug resistance.

Supervision or administration of medications is one of the key roles in the care process. It was evident from interviewing primary and secondary caregivers that there is an intensive adherence education programme prior to starting treatment. During pre-treatment counselling caregivers learn about the importance of adherence, how ARVs are taken and possible side effects of the drugs. Caregivers in this study showed a lot of commitment in giving children medications and giving the medication at exact times twice a day. The high commitment displayed by these caregivers could be influenced by the positive impact of treatment on the health of the children. Hunter (2007:22) asserts that "the confidence in providing care is closely tied to the condition of those they care for: When the ill person recovers slightly they feel more confident." Pontali (2005) and Shah, (2007) also concluded that a caregiver's belief in ARV therapy and improvement in health status are motivating factors in ensuring adherence. Carers in this study were delighted at the improvement in the health of the children.

Children, just like adult patients are given a month's supply of ARV's at each visit. This means frequent travelling to the treatment centre. The maximum distance travelled in this study was 120 kilometres. Lack of money to pay for transport is a major challenge to most caregivers. The importance of this cannot be emphasized enough. For several of the carers funding the equivalent of ten Rand for the return trip was daunting. It meant borrowing from family and friends. Yet remarkably, these carers all went to great lengths to make sure the child did not miss an appointment. For some this involved a round trip with no assured transport. They had to hope for additional assistance. This has a negative impact because if the caregiver is not able to raise the transport money the child may miss appointments and thus interrupt treatment. Interviews with secondary caregivers revealed that lack of money was the main reason why children do not come for check-ups. This shows that even though treatment is available and free, people may drop out if they are not able to cope with the financial demands. Thus, although treatment is available in principle to all who need it for many people accessing and maintaining treatment is a major problem. . The impact of transport costs on adherence has been raised by numerous studies amongst them Akintola, 2004; Kgathwane, et al., 2004; Oluwabemiga, 2005; Kajura, et al., 2006 and Kane, 2008).

The qualitative and quantitative findings of this study have demonstrated that caregivers are discharging their roles under very difficult financial conditions. Low income reduces the capacity of the household to provide for the needs of the children and other family members. In this study, households had few resources at their disposal to provide care. This was compounded by the fact that households had many dependents which further stretched the meagre resources. An overwhelming majority of caregivers (44 out of 49) were unemployed and had limited sources of income. The majority of caregivers pointed out that the lack of money was the most difficult aspect of caring because of not being able to meet the needs of the sick child and other family members. UNICEF (2005b:7) asserts that "where older people have difficulty in caring for fostered children this is more likely due to low household incomes than age." In the absence of social security for the unemployed, many households had difficulties in providing food, and other basic needs. Some caregivers relied on the orphan care ration and the old age pension, which is for men and women aged 65 years and above. However, the findings of this study have shown that most grandmothers caring for children did not have a pension to supplement their income because they were still too young to claim it. When asked what they thought should be done to help them cope with care giving, the overwhelming majority indicated that money would make a big difference. This is because if there was some financial support they would be able to meet the needs of the household. This finding agrees with Moore and Henry (2005) and Hunter (2007) who reported that caregivers felt that money would make a big difference in the care process. Previous studies conducted in Botswana and elsewhere on caring have corroborated that poverty is a major challenge in the care process. The strain on household resources can push families into deeper poverty (Lindsay, et al., 2003; More and Henry, 2005; Heyman, et al., 2007).

The most common method of coping with financial constraints was to borrow money from relatives, friends and neighbours. The problem with this strategy was that the carers had difficulty in paying back the money and this led to the accumulation of debt. Others asked for assistance from relatives but this was not always forthcoming. Some caregivers opted to reduce expenditure on food and to buy cheap and basic food items. These coping mechanisms may lead to poor nutrition especially for children and may affect their development. The use of borrowing as a strategy to relieve the financial burdens placed on households has also been reported in the literature (Barnett and Whiteside, 2002; Oluwagbemiga, 2007). This strategy

is also employed by poor people in South India. A 2006 study reported that 67% of respondents used borrowing as the main method of coping (Duraismy et al., 2006).

One of the priority areas on the 2004 UNICEF framework for the protection, care and support of orphans and vulnerable children living in a world with HIV/AIDS is to ensure access to basic services such as education. Access to education leads to acquisition of knowledge and the development of skills which in the long term improve the wellbeing of children who are made vulnerable by HIV/AIDS (UNAIDS, 2004). The results of this study have shown that all children of school going age were attending school

Experience of stigma and discrimination was not common amongst participants; whether within the household or outside. Out of the five respondents who took part in the in-depth interviews, only one reported experience of stigma and it occurred outside the family. However, while direct exposure to stigma was rare, fear of it was very common.

The results have shown that disclosure of an HIV positive status is a complex and difficult matter. It is complex because the outcome cannot be guaranteed. In some instances, disclosure has negative outcomes such as rejection and discrimination, as experienced by one child in this study. The class teacher knew the HIV status of the child and told the classmates. This resulted in other children ridiculing him and distancing themselves. In some cases, it facilitates support from relatives and the community. This is consistent with other studies, which have reported the advantages and disadvantages of disclosure (Klitzman, et al., 2004; Ameleh, 2006; Kajura, et al., 2006). Because of the uncertainty of the outcome, disclosure is a selective process. Deciding who to disclose to was a process of careful consideration of factors such as trustworthiness and anticipated support. Most of the caregivers in this study had disclosed the status of the child to some family members but not to all, and to people outside the family especially the child's teacher. External disclosure was motivated by the need for support such as permission to take the child for hospital visits. In all cases except one, the school was supportive and offered to assist the family in making sure the children were issued pills on time. The issue of selective disclosure in this study is consistent with other findings (Almeleh, 2006; Klitzman, et al., 2006).

The results have shown that caregivers have difficulties disclosing the HIV positive status to the child. Consequently most children had no idea why they are continuously taking medications. Health providers interviewed agreed that children were not told their HIV status.

Failure to disclose to the child has been reported by other studies. In the 2006 study in Tanzania, Kajura, et al, observed that children had not been told their HIV status and why they were taking treatment. According to the service providers interviewed in this study, this has a negative impact on adherence especially when the child matures to an adolescent. They reported that in some cases children become rebellious once they are told their HIV status. They displayed their discontent by refusing treatment, becoming angry with caregivers and showing delinquent tendencies.

Assistance from other households, relatives, friends and the community at large is vital in the care process because it supplements the efforts of the affected household and helps it cope with the heavy demands of care giving. Previous studies have reported that social support from the extended family and the community influences the commitment to care (Moore and Henry 2005). The findings of this study have demonstrated that the extended family was the main source of support to affected households. While the majority of children in the study were cared for by their biological parents, all orphaned children were cared for by close relatives, especially grandmothers. Child-headed households or childcare being provided by non-relatives was not observed in the study. This demonstrates the significant role played by the extended family despite the hardships they face such as inadequate income to provide for the needs of the child. Taking in additional members can worsen the economical demands on households. For the child, being cared for by a relative is beneficial because the child is likely to know the care provider. It also ensures continuity of care because in most cases the carer had been involved with the child before the death of the parent. This is consistent with other studies which have demonstrated the importance of the extended family as a social safety net (Kipp, 2006; Orner, 2006; Rajaraman, 2006). On the other hand some studies have found that the extended family was no longer a reliable source of support for families affected by HIV/AIDS because of its own economic difficulties. Because of poverty, most households cannot afford to meet the needs of its own members let alone help relatives.

There are many NGO's and community based organizations (CBO's) operating in Botswana. Most of them are based in urban areas and large villages. There were no NGO's and CBO's working to combat or mitigate the impact of the epidemic in the villages where the respondents reside. Thus, participants were not getting any support from NGO's or CBO's. Support groups of those living or affected by HIV/AIDS are an important forum to share

experiences and motivate each other but these were not established in the villages where the respondents lived. Caregivers had never received any support from the private sector either.

While the focus of this study was on primary caregivers, the results also revealed a lack of psychological support for secondary caregivers. Interviews with health workers revealed that the nature of their work was stressful and feelings of distress were a common manifestation. The emotional burden on health workers could be explained by the fact that they are dealing with an incurable disease that causes high mortality and immense human suffering. Health workers spend a lot of time with sick people. They see people die everyday and they watch the agony and suffering of the grieving family. Interviews revealed that the emotional burden they shoulder from their care giving roles was affecting their relationships outside the workplace. Stress is also caused by the heavy workload and the difficult cases they handle on a day to day basis. As a result, feelings of fatigue, anxiety and emotional exhaustion were common themes in the interviews. These stressful situations could eventually lead to burnout and may compromise the quality of care provided. While health workers identified stressful situations they encounter it was evident that there was no programme in place to address them.

CHAPTER 8

CONCLUSION AND POLICY RECOMMENDATIONS

In Botswana antiretroviral therapy has been provided through the public health sector since 2002. The aim of providing therapy was to save and improve the quality of lives of people living with HIV/AIDS. Availability of ARV therapy means that children could also access treatment. As a result treatment for children was integrated into adult treatment sites. However, treatment for children poses particular challenges to both health providers and family caregivers. It was against this background that this study explored the lived experiences of caregivers of children who are on ARV therapy. In an attempt to understand the experiences of care providers the study asked questions such as: What is it like to care for a child who is on ARV therapy? The study also explored the challenges encountered in the care process and the coping strategies devised to address them. The study wanted to find out what kind of support caregivers received from the extended family and community organizations such as churches. The focus of the study was to elicit the views of primary and secondary care providers. The study also elicited suggestions on what could be done to create a supportive environment for care provision.

The study used a combination of qualitative and quantitative research methods. This combination, which is referred to as triangulation, is useful in validating data from other sources (Baumgartner and Strong, 1994). The study used in-depth interviews and a structured questionnaire to collect data from respondents. The questionnaire collected socio-demographic data while in-depth interviews gathered the narrative data on the lived experiences of caregivers. Visits to the homes of those who took part in in-depth interviews were conducted in order to supplement information already collected. These visits gave me an opportunity to meet people in their home environments and afforded me a chance to better understand the conditions they were living in. The study was conducted in Mahalapye Sub-District, Botswana. Participants were selected at Mahalapye Hospital which started providing ARV therapy in October 2003.

Summary of Findings

While the government is committed to the universal access of ARV therapy, the study has shown that there are disparities in the provision of care. Equal access to treatment is still a challenge. Treatment is not available at all the levels of the health care system in the district.

The lower levels of the health system (clinic and health posts) are under-resourced in terms of personnel and physical infrastructure to support the roll-out of ARV therapy. Where treatment centres are located in the district, they are located in the main villages. This has disadvantaged the rural population who have to travel long distances to access treatment. The financial burden of accessing treatment was an overwhelming concern raised by participants. Service providers also pointed out that lack of money for transport was the main reason why people miss appointments and subsequently default from treatment. Accessing treatment was done at the expense of other household needs such as cutting expenditure on food.

The study has demonstrated that the burden of care was predominantly carried out by women who already had other domestic tasks. Many caregivers in the study had to manage the dual roles of being a caregiver and being HIV positive themselves under conditions of severe financial distress. It was evident that the burden of caring placed on women limited their income earning capacity. Most could not look for jobs outside the home because there was nobody to take care of the children in their absence.

High levels of income poverty were observed and this was attributed to high levels of unemployment. Limited income in most of the households led to material deprivation such as a shortage of food and other basic necessities. Nutrition plays an important role in disease progression. Yet, food security was a major challenge facing caregivers in the study. Caregivers talked about instances where they had to give medications to a child who was hungry contrary to what was prescribed. Even in households where they received the orphan care food ration, this was not enough to keep up with the nutritional needs of the family.

Most caregivers used government departments as the main source of support. Support from relatives varied widely with some receiving little or no support.

The primary and secondary caregivers agreed on most of the challenges facing people looking after a child with HIV infection except adherence to treatment. The former reported good adherence to treatment while the latter stated that there was poor adherence amongst children.

The study revealed lack of psychosocial support for health workers despite the fact that caring was a stressful undertaking.

Caring for a child on ARV therapy places considerable demands (time and resources) on care providers. Despite that caring for the children was a high priority for caregivers. Therefore, it is important to devise systems to help households to provide care to those affected by HIV/AIDS.

Recommendations

While the government of Botswana is committed to universal access to ARV therapy this study has identified challenges that have the potential to negatively affect this policy. It is imperative that public sector interventions are put in place to strengthen the capacity of households so that they can continue to provide care. In view of the above, the following policy recommendations are proposed.

Decentralize ARV Programme

Currently ARV therapy is provided in all hospitals and a few clinics in the country. As stated earlier, this arrangement involves a lot of travelling to the treatment sites. This in turn exerts a lot of pressure on the meagre household resources of poor families. Therefore, ARV therapy should be provided at all the levels of the health care system in order to make treatment more accessible. When participants were asked to name the support that would ease the burden of caring for children on ARV therapy, the third commonest response after money and food was to bring ARV therapy nearer to them. The proposal to roll-out ARV therapy to the lower levels of the health system is made in full awareness of the budgetary implications. However, the roll-out may benefit the entire health care system because of the developments that accompany ARV therapy such as upgrading of infrastructure, establishing information technology systems and strengthening personnel and training of staff (Ruxin, 2005). The other alternative is to use mobile clinics in remote areas in order to reach more people.

Introduce Quarterly Visits

The current practice is that all patients are given a 30 days supply of drugs at each visit. This arrangement causes frequent trips to the treatment centre. Furthermore, patients and caregivers have to come back on different dates for blood tests such as CD4 and viral load counts. This practice places a burden on poor households. It is also difficult for the few who are working to frequently take time from work to accompany the child for review.

Therefore, it is recommended that patients who have a good adherence record and are clinically stable should be given a 90-day supply of drugs and be reviewed by the doctor on a quarterly basis rather than monthly. It is also recommended that any blood tests that are required should be done at the time of the medical review to avoid return trips. This would reduce the number of visits to the treatment centre and in turn relieve some of the financial pressure on households.

Poverty Alleviation

The findings of this study have demonstrated that children live in poverty-stricken households. It is evident that the capacity of the families to care for children is constrained by a severe lack of resources, especially income. Household poverty limits the ability of families to provide care. The study has identified that most caregivers are single women without income. Lack of income affects household food security and other basic needs, travel costs and access to services. Most caregivers (55%) reported a monthly income of less than P300.00, which is not enough to sustain a family. This is compounded by high levels of unemployment. In this study, 90% of the caregivers were unemployed. In the absence of social security support for the unemployed caregivers are grappling with meeting the demands of care. Consequently, they have devised coping mechanisms such as reducing expenditure on food, which may have a negative impact on the growth of the children. Therefore, it is crucial for the government to devise policies that will support children living in poverty stricken homes. The following poverty alleviation strategies are recommended.

a). Re-Design the Orphan Care Programme

The focus of the orphan care programme is on provision of material support to households with orphans. This policy uses orphanhood as the main criterion to access services. This excludes vulnerable children whose parents are alive but living in poor households. This study has shown that most children are taken care of by their biological parents who are not able to raise enough income to sustain their families. Therefore, it is recommended that an inclusive policy be developed that will target all poor children and families without distinction.

b). Introduce the Child Support Grant

Another possible policy response to support children in poor households is to introduce a child support grant. A child support grant involves financial support paid to primary

caregivers to provide for the needs of the children. In countries like South Africa where this grant is implemented it has an age limit and an income threshold for eligibility. Studies have shown that the child support grant plays a crucial role in alleviating household poverty, since the money received helps provide food, meet travel costs and other household needs (Booyesen, 2004; Kane, 2008).

c). Transport Subsidies

When participants were asked to name assistance that could make the biggest difference in the care process, the commonest response was money for transport. Interviews have shown that caregivers are struggling with transport costs to access ARV medications. While treatment is free in the public health sector, it is evident that transport costs may be a barrier to access services. Failure to honour medical appointments is mainly attributed to lack of money for transport. Therefore, it is recommended that government should consider an option of providing transport to outlying areas and subsidizing transport costs for caregivers of children who live in poverty.

Strengthening Psycho - Social Support

Psychosocial support is a crucial component of the care process that helps caregivers to deal with challenges. Lack of support was a recurring theme in data analysis and this involves lack of spiritual support, emotional support, financial and material support. The few who reported that they were receiving some kind of social support indicated that it was not regular. Most caregivers depended on state institutions for support. The following interventions are proposed to strengthen psychosocial support.

The results have highlighted that counselling tends to be emphasized before treatment is initiated. Subsequently counselling is only done when there are adherence problems. Also, it has been observed that counselling sessions only target caregivers with little focus on children. Counselling and education of children is recommended to gradually prepare them to take responsibility for their treatment as they transit from childhood to adolescence and adulthood.

It is recommended that counselling should be offered at certain intervals to affirm the commitment of the caregivers and as a way to foster adherence. Counselling should address issues of disclosure, adherence and challenges to treatment. Individual counselling could also help the caregiver to make plans for the child in case s/he dies.

As stated earlier, a support group is an important forum where caregivers could meet and share experiences and coping strategies. Support groups could also start income generating activities to improve the income of members. It was evident that caregivers were not members of any support group. It is therefore recommended that health workers in collaboration with civil society organizations, if they exist should facilitate the formation of support groups for caregivers and child peer support groups in each village where there is more than one person/child on treatment.

Policy

All of the recommendations of this thesis have implications for policy. They involve the diversion of more state resources to the treatment of HIV/AIDS to ensure a successful outcome. Further studies should investigate the cost implications and the benefits of making these investments. Equally as important, or perhaps of greater importance is to change the concept of policy as internal to the organisation of a service. Where the service involves people, such as the provision of ARV treatment to those with AIDS, policy should not stop at the gates of the clinic or hospital but should embrace and include the people who receive the treatment and their needs.

This thesis has outlined the experiences of providing care to children on ARV therapy. These experiences will help to gain a better understanding of the needs of care provision. The study has shown the difficulties and constraints encountered in the care provision at household level. It is therefore imperative to devise mechanisms to strengthen the capacity of households caring for children affected by HIV/AIDS.

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Appendix 1: Consent Form

University of Cape Town

Department of Political Studies

Rondebosch. 7701

Research: **EXPERIENCES OF CAREGIVERS OF CHILDREN WHO ARE ON ANTIRETROVIRAL THERAPY**

I kindly invite you to take part in a study that aims at exploring and describing the experiences of caregivers of children who are on ARV therapy. I believe that you have experiences that could be of value to the understanding the needs of caregivers.

Participation in this study is voluntary and you may choose not to take part. You may discontinue your participation at any time without jeopardizing the future care either to yourself or your family members.

Interviews and completion of the questionnaire will take about 30 to 45 minutes of you time. The interview will require you to share your experiences on caring for a child who is on ARV. The questionnaire will ask for personal information such as age, level of education and household income. You are at liberty not to respond to questions that you do not feel comfortable discussing.

Information collected from you will be confidential and will be stored in a secure place where it can only be accessed by the researcher. Your name or any other characteristics that may be linked to you will not be used in the study. Instead, codes or pseudo names will be used to label the questionnaires and audio tapes.

This study will have no immediate benefits to you, but the findings will be useful in helping organizations to know the issues relating to care giving. There are no major risks anticipated in taking part in this study. You are encouraged to discuss any difficult feelings you may experience as a result of taking part in this study.

There are no financial costs that you will incur as a result of taking part in this study. You will not be paid for participating in this study.

You are encouraged to ask any questions that you may have about this study and your participation. Should the need to contact me arise, please feel free to contact me on the contact details below.

By signing this form, you are indicating that you understand the nature of the study, the right to voluntary participation, confidentiality, benefits and risks and that you agree to participate in this study.

Participant's Signature

Date

Investigator's Signature

Date

Researcher

Keitumetse Maapatsane

Tel: 72679655

Email: kmaapatsane@gmail.com

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Appendix 2: Semi-Structured Interview Guide

- 1. What are your experiences of caring for a child who is on ARV?**
- 2. What kind of support do you receive from the following support systems?**
 - Family**
 - Church**
 - School**
 - Community**
- 3. What do you think are the challenges of caring for a child on ARV?**
- 4. Can you think of any kind of support you need and you are not getting it at the moment?**

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Less than 6 Months

6 - 12 Months

12 - 18 Months

18 - 24 Months

2 - 3 Years

3 Years and Greater

11. How old is the child _____

12. When did the child start ARV therapy _____

13. Number of children under 18years in the household _____

14. Distance from treatment centre _____

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Appendix 4: Interview Guide for Secondary Caregivers

1. What are your experiences in caring for children who are on ARV therapy?
2. What are the main challenges you face in supporting children to adhere to ARV therapy?
3. What support systems are available for caregivers of children who are on ARV therapy?

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