FACTORS DESCRIBING LATE UPTAKE OF ANTIRETROVIRAL DRUGS TO PEOPLE LIVING WITH HIV AND AIDS: THE CASE STUDY OF SHDEPHA+ MEMBERS IN DAR ES SALAAM, TANZANIA

By

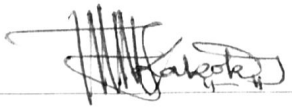
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A Dissertation Submitted in Partial Fulfilment of the Requirements for the Degree of Master of Public Health of the Muhimbili University of Health and Allied Sciences

October, 2007

CERTIFICATION (For examination)

The undersigned certifies that he has read and hereby recommends for examination a dissertation entitled **FACTORS DESCRIBING LATE UPTAKE OF ANTIRETROVIRAL DRUGS TO PEOPLE LIVING WITH HIV AND AIDS: THE CASE STUDY OF SHDEPHA+ MEMBERS IN DAR ES SALAAM,TANZANIA** in fulfilment of the requirements for the degree of Master of Public Health of the Muhimbili University of Health and Allied Sciences .



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Date: 20/10/2008

DECLARATION

AND

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ACKNOWLEDGEMENT

I thank the Almighty God, for giving me strength throughout the time I worked on this dissertation. I owe many thanks to many people who made invaluable contributions in different ways to enable me reach this final stage.

My deepest and sincerest gratitude is first extended to Dr. D.C.V. Kakoko, my supervisor, who tirelessly provided me with talented technical advice; unfailing guidance, moral support and criticism that made me accomplish this task.

I owe many thanks to the administration of SHDEPHA+ in Dar es Salaam for allowing me to conduct this study in their organization. I extend this acknowledgement to the members of the organization who agreed to participate in this study, may God bless them.

Frankly speaking, I am indebted to numerous people who assisted me in one way or another, though not explicitly mentioned in this brief acknowledgement. I would kindly ask all of them to accept my sincerest appreciation for the support they provided me in the accomplishment of this study.

DEDICATION

This study is dedicated to my parents Mr. and Mrs. Mayala who enabled me reach this stage, whom without their guidance I would not have reached . May Almighty God bless them.

ABSTRACT

In Tanzania, HIV/AIDS is continuously spreading at an alarming rate. Many modalities of intervention are on use including care and treatment of people living with HIV and AIDS with antiretroviral therapy (ARVs). However, ART intervention is not fully achieving its goals due to late antiretroviral uptake by people living with HIV and AIDS. The study based on five objectives; to explore the extent to which SHDEPHA+ members were aware of antiretroviral therapy before they were initiated on treatment, to explore lapse time between knowing sero-positive status and initiating antiretroviral therapy among SHDEPHA+ members who are on antiretroviral therapy, to explore perceptions that SHDEPHA+ members held before they were initiated on treatment, to assess barriers to early uptake of treatment and lastly to examine opinions of people living with HIV and AIDS on early use of antiretroviral therapy. The study was qualitative and used semi-structured interviews. Findings showed that awareness on availability of facilities providing care and treatment for PLHA is generally poor, patients start treatment at very low CD4 counts, negative perceptions on ART were held before initiating therapy. Some reasons for this were; personal, governmental, service provider's attitude, and health systems factors. These were compounded with denial, discrimination, stigma and poverty. Recommendations from the study were that the government should make effort to sensitize the community to make use of the programme preferably using people living with HIV and AIDS and the Ministry of Health and Social Welfare should consider some policy changes based on the study findings.

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LIST OF ABBREVIATIONS

AIDS Acquired Immunodeficiency Syndrome

ART Antiretroviral Therapy

ARV Antiretroviral drugs

CDC Centers for Disease Control

CTC Care and Treatment Clinic

DOT Direct Observed Therapy

HAART Highly Active Antiretroviral Therapy

HIV Human Immunodeficiency Virus

MoH Ministry of Health

NACP National AIDS Control Programme

PMTCT Prevention of Maternal to Child Transmission of HIV/AIDS

SHDEPHA+ Services Heals and Development for People Living Positively with HIV/AIDS

THIS Tanzania HIV/AIDS Indicator Survey

VCT Voluntary Counseling and Testing

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND

Human Immunodeficiency Virus (HIV) is spreading at an alarming rate in Sub Saharan Africa. For instance, the UNAIDS report of 2005 reveal that 70 percent of adults and 94 percent of children are living with HIV/AIDS (UNAIDS, 2006). In Tanzania, the burden of diseases due to HIV/AIDS consumes 25 percent of hospital service resources, which pose great load to both the health care delivery system as well as service providers (Dominic et al., 2004).

Nevertheless, the advent of Highly Active Antiretroviral Therapies (HAART) has changed HIV/AIDS from an acute life threatening condition to a chronic disease (THIS, 2003/2004). Antiretroviral drugs are of three groups, nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, and protease inhibitors (Nischal et al., 2005). These drugs act by inhibiting replication of the viral proteins hence reducing viral load in the body. When the viral load has been reduced in the body, reconstitution of the immune system of the body takes place protecting the vulnerability of the body to various infections and other opportunistic infections, which would have occurred without these drugs (Chequer et al., 2002).

The Tanzania national health policy recognizes that good health is a major resource essential for poverty eradication and economic development (MoH, 2003). As health is a right to every citizen, the government of Tanzania established interventions to prevent spread of HIV such as introducing PMTCT, Care and Treatment Clinics (CTC) and

voluntary HIV counseling and testing (VCT). All these interventions are amplified by the introduction of Highly Active Antiretroviral Drugs (HAART) technology.

In Tanzanian setting, antiretroviral therapy (ART) is provided through CTC in accredited health facilities for HIV care with ART. According to the National AIDS Control Programme, CTC should incorporate services such as Direct Observed Therapy (DOTS) for tuberculosis, reproductive health, family planning and home care services (NACP, 2004). Other services include health education on pathophysiology of HIV infection, management of disease symptoms, behavior change education to reduce the transmission of HIV and orientation to the care and treatment programme.

Tanzanian NACP focuses on education and counseling about actions that may delay progression of disease and reduce co-morbidities. This is by addressing nutrition, food safety and clean water, routine clinical care and nutritional assistance to malnourished patients. Others are prophylaxis for opportunistic infections and assessing eligibility for ART using WHO clinical staging criteria and CD4 counts which identifies four stages of the disease.

First, is the clinically asymptomatic stage (mildly immune-suppressed) individual. This involves HIV positive individual with high CD4 cell counts. They come to clinic for periodic monitoring and the goal of care to these patients is to delay progression by treating and/or preventing opportunistic infection, advice on health life styles and to

enhance the likelihood of success of future treatment by improving adherence to prophylactic medication and visits.

Second, is the symptomatic HIV (moderately immune suppressed). Patients at this stage have compromised immune system but not eligible for ART. They are at risk to progress to full blown AIDS, so they need close monitoring. The goal of care at this stage is to delay progression by treating opportunistic infections and to enhance the likelihood of success of future treatment by improving adherence to medications and clinic visits.

Third and fourth, AIDS (treatment ready patients), these are patients who are eligible for ART. The goals of treatment and care for these patients are to reduce morbidity and mortality by aggressively suppressing viral load and treating opportunistic infection and to maximize the benefit treatment adherence to antiretroviral therapy. Stage four disease has AIDS defining illnesses such as Kaposi's sarcoma, Herpes zoster, Candidiasis and other opportunistic infections.

Tanzanian government has shown commitment into the improvement of accessibility of antiretroviral therapy to the community. This was reached in the United Nations General Assembly in 2006 where member states agreed to work towards the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010 (News and Events, 2007). This commitment raised coverage of antiretroviral therapy in Sub Saharan Africa from 2 percent to 28 percent within three years.

1.2 PROBLEM STATEMENT

Early antiretroviral drug uptake is an opportunity to fight AIDS epidemic. Several studies have documented importance of early use of antiretroviral drugs. On the one hand, initiating treatment early at CD4+ lymphocyte counts of 200 per micro liter has been associated with better treatment outcome (Tantivess et al., 2006; Van der Merwe, 2006; Kauf et al., 2001). On the other hand, late antiretroviral drug uptake has been associated with poor treatment outcome. For instance, initiating antiretroviral drug therapy at CD4+ lymphocyte count below 200 cells per micro liter has been associated with increased risk of death (Kaplan, 2001; Ahdieh et al., 2000; CDC, 2000).

Despite this, late antiretroviral drug uptake is still a remarkable problem facing efforts to fight HIV/AIDS epidemic in many HIV prevalent countries including Tanzania. According to the Tanzanian treatment guidelines, it is recommended that treatment should be initiated at CD 4+ lymphocyte counts of 200 per micro liter (NACP, 2004). To enhance this, CTCs have been opened in each district allover the country.

Despite the good coverage of CTC in Tanzania, patients present very late into treatment. This avenue alone seem not sufficient because people with HIV/AIDS delay initiating ARVs; it may be due to poor health delivery system, attitudes of people towards ARVs, attitudes of people towards VCT services for HIV/AIDS, culture, perceptions and beliefs on ART services and social economic status.

As late antiretroviral therapy uptake has not been studied in Tanzania, the present study intended to understand factors describing late uptake of antiretroviral drugs.

1.3 RATIONALE

This study is going to bridge the gap of unknown factors, which describe late uptake of antiretroviral drugs. Knowledge of such factors will help to improve intervention strategies targeting early treatment of people living with HIV and AIDS.

Knowing factors describing late uptake of antiretroviral drugs will help in the modification of treatment guidelines, policy changes and bring change in the practice of managing people living with HIV and AIDS (Edwin, 2007).

This study therefore, will provide information, which is important in improving early uptake of antiretroviral therapy to mitigate the impact of HIV and AIDS and also control other diseases which are secondary to HIV and AIDS.

The other reasons of conducting this study is to get stakeholders opinions on how to improve early uptake of antiretroviral therapy and can give way forward on how to improve antiretroviral therapy services.

Furthermore, this study will be a catalyst for other researchers to conduct further studies on late uptake of antiretroviral drugs.

1.4 OBJECTIVES

1.4.1 Broad objective

To determine factors describing late uptake of antiretroviral drugs among people living with HIV and AIDS.

1.4.2 Specific objectives

1.4.2.1 To explore the extent to which members were aware of antiretroviral therapy services before they were initiated on treatment.

1.4.2.2 To explore time lapse between knowing sero-positive status and initiating antiretroviral therapy among SHDEPHA+ members who are on ARTs.

1.4.2.3 To explore perceptions that SHDEPHA+ members had before they were initiated on treatment.

1.4.2.4 To explore whether late uptake of antiretroviral therapy were associated with unavailability, inaccessibility and unaffordability of therapy to people living with HIV and AIDS.

1.4.2.5 To explore opinions of people living with HIV and AIDS on antiretroviral therapy services.

CHAPTER 2: LITERATURE REVIEW

Human immunodeficiency virus (HIV) infection is incurable. Use of antiretroviral drugs (ARVs) is therefore the most effective intervention to prolong patient lives (Tantivess et al., 2006). Combination antiretroviral therapy (ART) widely introduced in developed countries since the mid–1990, has resulted in a dramatic decline in opportunistic disease and therefore HIV- related mortality (Detels et al., 1998; Pallela et al., 1998; Tantivess et al., 2006). Furthermore, treated patients regain close to normal quality of life including working capacity (Nischal et al., 2006). Since HIV largely affects younger – middle aged adults, expanding treatment access would prevent break down of societal structure and restore economic development.

Despite good work ARVs are doing, they are facing a multitude of obstacles in dispensing these drugs. Most of our patients start therapy late at low CD4 cell counts. For instance, in a study done in United Kingdom to audit Clients on antiretroviral therapy it was found out that only 30 percent of the patients initiated treatment according to the recommended treatment guideline (Edwin, 2007). The study reported that these patients had reasons for their attendance to the service providers, diseases like renal failure, chronic illness and others.

Other factors describing late uptake of ARVs may be related to community attitude towards therapy, attitudes towards voluntary counseling and testing, beliefs and perceptions, social economic status and factors related to the health delivery system.

Late uptake of antiretroviral drugs has been associated with increased risk of death and side effects. For instance, in a study done to 159 patients who initiated treatment late at CD4+ lymphocyte count below 50 cells per cubic milliliter, 22 patients equivalent to 13.8 percent had severe adverse effects and were discontinued from treatment (Sungkanuparch et al., 2005).

Improving access to antiretroviral therapy to people living with HIV and AIDS is important so as to reduce mortality and hospitalization (Chequer et al., 2002), hence reducing working burden of the health system (Dominick et al., 2004). Integrating services in the health system has been shown to improve access and facilitate early uptake of antiretroviral drugs. For instance, in a study done in Gauteng province South Africa reported early uptake of antiretroviral drugs by integrating antenatal clinic and care and treatment clinic (Van der Merwe et al., 2006).

Improving the health delivery system is important because most people living with HIV and AIDS are marginalized and vulnerable to deprivation hence proper care and treatment depends on public services (Tantivess et al., 2006). As such, uncommitted public servants can be source of late uptake of antiretroviral drugs when cost component comes in for a service intended to be given free of charge. For instance, India a country with one of the largest HIV epidemics in the world has managed within 2 years of global fund support of $51,946,000 to disburse $5,543,000, which denies services to the society (www-africa-union.org, 2006).

Health seeking behaviour is influenced by an individual's social economic status, as individuals who can not afford costs involved in service provision delay in uptake of antiretroviral drugs. These costs are incurred in transport to the clinic, doing preliminary investigations such as liver function tests, renal function tests and others.

A study done in Uganda Mildmay Center among 100 drug defaulters found that 60 percent defaulted due to poverty, fifteen percent due to gender and cultural issues, thirteen percent lack of disclosure to children, spouses or employers, three percent loss of hope and two percent due to side effects (Bakunda, 2002). Another study done in rural Kisesa district in Mwanza, Tanzania shown same

Sometimes the life style pattern of an individual may hinder uptake of ARVs. For instance, in a study done in India it was reported that life style pattern of an individual can make late uptake to antiretroviral therapy; things like alcoholism which make an individual hesitate starting medication, lacking family support in seeking care (Nischal et al., 2005).

Beliefs, perceptions and culture of the community may influence late uptake of ARVs especially when they are negative. For instance, a study done in South Africa found out that ART among some interviewees were not perceived as new but one of many alternative therapies for HIV and AIDS. Many expressed a lack of excitement about the introduction of ART and little change in their attitudes concerning the epidemic (Chopra et al., 2006).

Same picture is seen in Tanzania where the

Tanzania National AIDS Control Program reported that some patients in the country have wrong perceptions about antiretroviral therapy and disease causation; they believed that it is caused by bewitchment. This contributed for not attaining the country target of putting 500,000 patients on antiretroviral therapy by 2008 (NACP, 2004). However, current data of mid September 2006 showed that there are only 49,915 patients on antiretroviral therapy. This is even far below 2005 and 2006 end of year target of covering 66,000 patients and 104 patients on antiretroviral drugs respectively (NACP, 2004; Plus News, 2007).

Attitudes of the community towards antiretroviral therapy may have an influence on the time patients begin treatment (Schrimshaw et al., 2005). For instance, the emergency of drug side effects like lipodystrophy during HAART and its psychosocial repercussion could lead to decrease in adherence level or at least a worsening in the beliefs about drugs (Marin et al., 2004; Stoekle et al., 2006; Mshana et al., 2006). Positive attitudes towards antiretroviral therapy was associated with taking the medication, this was demonstrated in a study done in Australia (Kanouse et al., 1996).

Voluntary counseling and testing services is an important intervention to mitigate the impact of HIV/AIDS (THIS, 2003/2004). Little information is available on the delivery and impact of VCT in the general population of Sub Saharan Africa. Even less information is available on VCT specifically targeted to African men (Machekano et al.,

2000). If efforts are not strengthened on the increased delivery of VCT services, a number of individuals who are HIV positive without symptoms will be missed, causing delays in initiating antiretroviral therapy.

For instance, in a study done in Kunming City in China among injecting drug users on VCT services they considered themselves to have no risks for HIV/AIDS. Study results reported that 69.3 percent of the respondents pointed out that stigma and discrimination were major reasons why many drug users were not accessing VCT. However 32 percent of these respondents had risks for HIV and AIDS because they were sharing injecting needles and 65.3 percent of the respondents had unprotected sex with casual sex workers (Kobusingye, 2004).

As it has been shown in this study, individuals disregard themselves to have risks for HIV and AIDS and they miss an opportunity to be tested hence being diagnosed late and delay to initiate antiretroviral therapy.

Positive attitudes towards VCT services have been shown to facilitate early diagnosis and probable early uptake of antiretroviral therapy. A study done in United States reported decrease of Maternal to Child Transmission of HIV and AIDS due to enhanced prenatal HIV testing and increase use of HAART by HIV positive women (CDC, 2004).

Other barriers to initiate antiretroviral therapy which can contribute to late uptake of antiretroviral drugs include pros and cons of starting therapy, ability to adhere to therapy,

low knowledge of HIV and AIDS, lacking experience with antiretroviral drugs and food requirement (Mshana et al., 2006; Nischal et al., 2005).

CHAPTER 3: METHODOLOGY

3.1 STUDY AREA

The study was conducted in an organization called SHDEPHA+. This is a non – governmental organization using an acronym SHDEPHA+ that means Services Heals and Development for People living positively with HIV/AIDS (PLHA). SHDEPHA+ is the first and oldest HIV/AIDS non-governmental organization in Tanzania operating since November 1994 (under registration 50. No.8216). SHDEPHA+ was formed from a group of fifteen HIV positive individuals on September 6, 1993 after deciding to mobilize their resources to fight the HIV/ AIDS epidemic and fight the stigma and discrimination of people living with HIV/AIDS. It has since then expanded nationally to 136 branches currently operating throughout Tanzania.

The reason for selecting this organization was that it has members from all the three Municipals and so enabled to get mixture of ideas. Also their members have had experiences on the research phenomenon of late uptake of antiretroviral drugs which was studied. Dar es Salaam was selected as it is a pioneer of the organization and its members expected to be experienced on the researched phenomenon.

3.2 STUDY DESIGN

The study was of a qualitative design. This design enabled the study to get the lived experiences of the researched individuals (Creswell, 2003). Qualitative study aimed at comprehending the participants lived experiences rather than achieving statistical power

and generalisable or replicable findings (Cresswell, 1998; Manen, 1990; Miles & Huberman, 1994; Patton, 1990). The focus of this study was factors describing late uptake of ARVs using SHIDEPHA+ as a case study. The reason for selecting qualitative design was due to its theoretical underpinning of qualitative research which assumed a personal view or way of perceiving and interpreting phenomenon. Through this, it was easier to gain deeper understanding of the participant's ideas, opinions, feelings and actions about late uptake of ARVs. Also qualitative was used because it has various techniques to generate data (Morse & Richards, 2002).

A qualitative research approach has disadvantages and advantages. On the one hand, qualitative research approach does not allow for generalization to a larger population as it depends on a small number of respondents (Denscombe, 1998; Patton, 1990; Silverman, 2000). On the other hand, qualitative research are normally organized into incidents that have concrete meaning to a reader, another researcher, policy maker or a practitioner as compared to pages of summarized numbers (Miles & Huberman, 1994).

3.3 STUDY POPULATION

Any field of inquiry must constitute a population (Kothari, 1992). Population constitutes a group of individuals with one or more common characteristics (Best& Kahn, 1998). As for the present study, the population was SHIDEPHA+ members who were on ART. SHIDEPHA+ has three sites in Dar es Salaam namely Kinondoni Municipal at Makumbusho ward, Ilala Municipal as the headquarter and Mbagala at Temeke Municipal. Study participants were recruited from all three sites. Table 1 presents study participants by age and sex.

Table 1. Study participants by age,sex and residence

Age(years)	Females	Residence	Males	Residence	Total
20-24	1	Mbagala	0	-	1
25-29	5	Mbagala	0	-	5
30-34	7	Ilala	1	Mbagala	8
35-39	7	Makumbusho	2	Ilala	9
40-44	10	Makumbusho	2	Makumbusho	12
45-49	2	Mbagala	2	Mbagala	4
50-54	1	Makumbusho	0	-	1
55-59	2	Ilala	0	-	2
Total	35		7		42

3.4 SAMPLING PROCEDURE

A sample is a small group of respondents drawn from the population in such a way that it represents all the key features of the population (Cohen, Manion & Keith, 2000). As for this study, purposeful sampling method was used to obtain study participants. This method was used in order to get the key informants with the richest information for the study. All key informants were recruited basing on their CD4 cell counts at which were started on antiretroviral therapy. According to the Ministry of Health and Social Welfare guidelines, the recommended CD4 cell counts of starting antiretroviral drugs are at 200 CD4 Cell counts, sometimes 350 cell counts if the patient has concurrent tuberculosis and others were started using the WHO clinical staging criteria (MoH,2004). Participants' level of CD4+ counts was identified from their treatment cards and interview process took place at a respective site a participant was recruited whether at Ilala, Makumbusho and Mbagala. The sample size was based on the saturation of information intended (Creswell, 2003).

3.5 RESEARCH INSTRUMENT

Semi- structured interview guide was prepared in English and translated in Swahili. The instrument was back translated into English. This aimed at testing whether questions we re having same concepts. All interviews were conducted in Kiswahili language because most of respondents could communicate well in Swahili language. The aim was also to ensure internal validity of the instrument that refers to collected information or data which are accurate, correct, true, and meaningful and which was right (Enon, 1998). Semi- structured interview guide was prepared by the researcher prior to the study. Simulation exercises were done using different individuals from the study group to test whether the instrument had questions which were relevant to the study topic, had good coverage of the research questions and gathered consistent information from the participants.

3.6 DATA COLLECTION

Data were collected by conducting interviews with each key informant using the tool. Pre - testing of the tool was done in different settings of the study sites. There was a simulation exercise to five respondents who volunteered to be interviewed after informed consent. These were obtained from the three research sites and the exercises were used as a guide to improve the instrument. It was important to see whether the set questions were meaningful to the interviewee and whether they gathered intended information.

The researcher recorded by writing all the information during the interview process and not latter. The information recorded was as narrated by the key informant. Any thing that

was not clear during the interview process was clarified by probing more to get very clear information according to the key informant's understanding, perception and opinion.

3.7 DATA ANALYSIS PLAN

The data which was generated from semi-structured interview guide in Swahili was translated into English. Data analysis was an ongoing process from collecting data. Such a process was important because both interviewer and interviewee needed clarification of the interview question and information which was given to have meaning. Data analysis was done daily after data collection. Data from field notes was organized and coded under subheadings reflecting specific objectives. The coded data was described as they were narrated by the key informants. Latter the described data was interpreted to give the meaning.

The presented data was also discussed using the relevant and available literature. After the discussion, recommendations were given according to the information obtained from the study and the available literature.

3.8 ETHICAL CONSIDERATION

Gaining entry to a research site and obtaining ethical clearance are the responsibility of the researcher (Creswell, 2003). Prior to the study ethical clearance was obtained from the Muhimbili University College of Health Sciences. The permission to conduct the study was sought and obtained from the Executive Director of SHDEPHA+ and from site supervisors.

Moreover, the informed consent was sought from each key informant with prior explanation of the aim of the study, benefits for participating in the study and objectives of the study. That was preceded by the researcher introducing himself to each participant.

The interview guide contained an informed consent form (Appendix 4). The interviewer carefully read the form to each participant before starting the interview process. The informed consent form clearly stated voluntary participation, confidentiality of the interview process on the information given. There was also role of participants and the importance of their participation and the right to withdraw at any stage during the interview process. Furthermore, informed consent form used understandable language. There was also a chance for informants to ask questions for clarification (if there were any). Also participants were informed the expected duration for session to allow voluntary participation.

It should be noted that ethical challenges might emanate from conflict of interest among site supervisors, researcher and participants (De, laine, 2000).This may, for example, be by supervisors influencing participation of participants. As for this study, the site supervisors did not try to influence or limit participants from revealing information they felt regarding the study. Likewise, site supervisor did not influence the voluntary participation of interviewees.

The other challenge was the likelihood of interviewees exaggerating some of the information relating to their problems hoping that study findings would bring immediate changes in their programme were clearly observed during the data analysis and

interpretation of findings. This challenge was taken care of by clearly explaining the study aim and voluntary participation prior to the interview process.

Participants were assured of anonymity by being informed that their names will not be included in the research report. Regarding confidentiality, informants were told that the information collected will be stored in researcher's confidential files to avoid leakage of the information before being destroyed.

As a part of researcher's obligation, information gathered from the present study will be kept for not less than three years post this study against any reactions related to the study.

CHAPTER 4: RESULTS AND DATA ANALYSIS

4.0 INTRODUCTION

This chapter presents the findings of the study entitled "Factors describing late uptake of antiretroviral drugs among people living with HIV/AIDS: The case study of SHDEPHA+ members in Dar es Salaam, Tanzania'. Findings are presented under the specific research objectives.

4.1 SHDEPHA+ members' awareness of ARV Therapy before they were initiated on treatment

It was found that most members interviewed were aware of where they could go to test for HIV and where they could obtain antiretroviral therapy. When they were probed where they obtained information, it was found that most of them learnt of these services from health facilities, some from non governmental organizations and least from radio and relatives. It should, however, be noted that non-governmental organizations also are hospital based since they provide services to general outpatients including care and treatment for people living with HIV and AIDS. Most of the interviewees who got information about availability of antiretroviral therapy services from health facility

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settings were not intentional because most of them were seeking treatment for their other health problems. For instance, a 43 year old female respondent reported that,

> "...I got this information about availability of testing services for HIV/AIDS and antiretroviral drugs in 2002 ... when I was attending an antenatal clinic as we were informed about these services before antenatal services..."

During the interview, it was revealed that most of respondents got information about availability of antiretroviral therapy services when they attended health facilities due to chronic medical conditions such as recurrent and chronic fevers, tuberculosis, kaposis sarcoma, herpes zoster and other AIDS defining illnesses. One female respondent aged 44 years narrated as follows,

> "...I got the information about availability of these services when I attended hospital... because of herpes zoster..."

Those who reported that they got information from their relatives explained that it were their presenting symptoms which lead their relatives to advise them to attend antiretroviral therapy services. Moreover, there were some cases when some of SHIDEPHA+ members could not believe radio information until such information was clarified by the second person. A 24 year old female respondent narrated as follows,

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> "...I heard this information from radio in the first time... and I wondered whether it was true, I thought it was just propagandas, but I believed them when my mother in law told me that information was real not politics as usual..."

The interview process also gathered information about whether delay in the community being told on the availability of HIV/AIDS testing services and where to get antiretroviral drugs caused most patients to delay initiating antiretroviral drugs. Diverse views were obtained from the interview, as some of the respondents reported that the issue is not public awareness but a will to dare voluntarily go and check for HIV infection. Some of the reasons mentioned for not testing which hinder early uptake of antiretroviral drugs include fear of stigma, misperception of the disease and fear of the effects of antiretroviral drugs.

Some of the informants said that if one tests positive people would point a finger on him or her as a sinner by saying that you got the disease for being unfaithful. One may start by being slowly separated from relatives, and some, even their marriage may be broken. For instance, one female respondent aged 32 years confesses that,

> "...I was divorced after my husband knew I was infected with HIV, when I showed him my HIV positive results; he said it is not possible for him to have the disease and it's me who brought the disease. He objected to test and left me home alone to avoid shame and now I am hearing he is having sex with

other women even without knowing his status and as well infecting them also …"

Similarly, another female respondent aged 50 years witnessed that,

"…This disease is very stigmatizing, my own daughter stigmatized me when I needed her help. She was married to a man and they were doing well, when she was told that I was sick she stopped to come home to help me, she was looking at me as if I was not her mother. She learnt a lesson when her husband was jailed and returned home seeking forgiveness; because I was her mother I forgave her …"

They also reported that some patients delayed in drug use because of the perception attached to the disease. Some associated the disease symptoms with sourcerer (witchcraft) as one male respondent aged 44 years reported,

"…We are seeing our neighbours with all symptoms of HIV and AIDS… claim that they are bewitched. Even if you try telling them the truth that these symptoms are due to AIDS and you had the same symptoms before you started treatment they reject. They come to realize the truth when it is too late and the disease has advanced…"

They reported that all these happen because people are not knowledgeable about the disease. For example, they do not know about what causes the disease.

Respondents also said that patients delay using drugs because of fearing drug side effects. Some claim that these medicines are poisonous and can kill. Because of this, they do not see a need to test for HIV as a result they get medical attention at late stage. A 34 year old female narrated,

> "...You know...people perceive that antiretroviral drugs are poisonous and can kill when you use them..."

Some respondents reported that lack of awareness of the availability of testing services for HIV and antiretroviral drugs availability cause delay in some patients accessing therapy. For instance, one male respondent aged 44 years reported,

> "...People are not aware of these services especially in rural areas because last year (meaning in year 2006) I visited my village where I left with very poorest health due to AIDS. I started ARVs in 2004 but when I told these fellows that I was an AIDS patient on ARVs they rejected even they were not aware that these services are available..."

Other respondents said that delay in initiating antiretroviral therapy was caused by not being aware of their status, as they visited health facilities several times when they were sick and being investigated without being told what the findings were. As one female respondent aged 45 years reported,

> "...I learnt my sero-positive status in 2006 as I was sick for a long time without knowing what my problem was. I remember in the year 2000, I was sent to hospital with my uncle and I was investigated. After my uncle talked privately with my doctor, I was told that my blood was not clean... that is why I am saying, it is not our problem but doctors problem for not telling us the truth..."

Other interviewees said that some of non governmental organizations dealing with care and treatment caused their delay in initiating therapy. When they initially tested and found that their CD4 counts were within eligible group to start therapy they were not started on ARVs. They added that they were told to wait because they were still physically strong until when they were bedridden that is when they started them on therapy. One female interviewee aged 43 years said,

> "...For sure people who initiate us on treatment cause our delay because I was tested and got positive results and when my CD4 counts were done I was in eligible group to start treatment but I did not start treatment because I was told that I was still physically strong. As time passed, my condition worsened until I was sent to the same facility on bed I started treatment ..."

They added that some of their relatives and friends due to this they transferred themselves to government facilities to get started on therapy at relatively right time.

4.2 Time interval between HIV+ve testing to introduction of ARV Therapy among SHDEPHA+ members

Results showed that all interviewees started taking antiretroviral below the recommendations of the national guideline for treating HIV/AIDS. Some interviewee said that they tested at a period when CD4 counts determination was not offered free off charge .hence they had to wait until these services started being offered free of charge. They were told to go and wait until their conditions had worsened before returning to the hospital. Some patients were started on treatment without their CD4 counts being measured or with only initial measurement levels. They said the problem was the availability of the instrument to check CD4 counts as one interviewee aged 42 year old reported,

> "...I tested HIV in 2000 but I did not have money to check for CD4 counts which amounted to 35,000 shillings so I had to wait until services were offered free of charge in 2004, and my CD4 counts when I was checked was 28..."

Other respondents said that they were troubled a lot with some institutions which were doing research. They said they tested them but not offered services when they were found to be unfit according their inclusion criteria without clear explanation as where else they could get same services. A 39 year old female respondent reported,

> "...When I tested my CD4 counts, it was 224 ... I was told that I am not fit in that study and being told that I have to seek services else where from that time I was troubled a lot until when I decided to cheat in the same

organization that it was my first time to visit their and they tested me again ... found out that my CD4 counts was now 124 and they started me on therapy..."

Table below summarizes CD4 counts on testing; starting ARVs time lapsed before starting therapy;

Table 2: Baseline CD4 counts,CD4 counts on treatment, Medical condition and time lapse before introduction of treatment

CODE	CD4 ON TESTING	MEDICAL CONDITION	CD4 ON THERAPY	TIME LAPSE
1	99	Tuberculosis	99	14 days
2	34	Opportunistic infections	70	3 months
3	21	Chronic illness	36	2 months
4	186	Chronic illness	186	1 months
5	121	Herpes Zoster	121	5 months
6	150	Chronic illness	28	6 months
7	234	Couple deaths	234	1 months
8	24	Opportunistic infections	50	1 year
9	180	Chronic illness	210	6 months
10	375	Chronic illness	200	2 years
11	-	Chronic illness	130	7 years
12	260	Herpes Zoster	68	6 months
13	280	Couple deaths	220	4 months
14	94	Chronic illness	94	2 months
15	1200	Chronic illness	76	2 years
16	157	Tuberculosis	200	9 months
17	60	Chronic illness	60	14 days
18	180	Couple deaths	180	14 days
19	33	Opportunistic infections	58	6 months
20	0	Chronic illness	-	2 years
21	-	Chronic illness	-	14 days
22	110	Tuberculosis	110	6 months
23	91	Chronic illness	91	2 months

24	70	Chronic illness	-	3 months
25	120	Chronic illness	90	1 months
26	6	Opportunistic infections	6	2 months
27	300	Couple deaths	300	2 months
28	224	Tuberculosis	124	1 year
29	4	Chronic illness	4	4 days
30	260	Chronic illness	-	6 years
31	121	Chronic illness	121	14 days
32	1	Chronic illness	1	2 months
33	-	Chronic illness	-	4 months
34	8	Chronic illness	8	2 months
35	-	Tuberculosis	201	1 year
36	156	Chronic illness	156	5 days
37	301	Couple deaths	301	3 months
38	7	Chronic illness	7	3 months
39	28	Chronic illness	28	1 months
40	250	Herpes Zoster	100	4 years
41	407	Chronic illness	172	8 months
42	178	Chronic illness	178	6 months

Table 2 results show that 20(47.6%) of informants have the same CD4 counts on testing and at starting therapy, and this was within 1 to 2 months. The other informants' time lapse was within 3 to 6 months.About 60 percent on interviewees tested HIV/AIDS due to recurrent and chronic illnesses and the rest 40 percent were due to couple deaths, opportunistic infections, tuberculosis and others.

The results also show that nearly all of the interviewed had a medical problem which made them to test for HIV. These medical conditions were chronic and recurrent illness,

tuberculosis, herpes zoster, stroke and other opportunistic infections. Other reasons were pregnancy and loss of husband. Table 3, one female respondent aged 39 years reported,

> "...I decided to test after my husband died ... I was worried because the cause of my husband's death was kept as a secret by doctors..."

Another concern of the interviewees was the issue of obtaining a treatment partner. They said it is not easy because some have no person they trust or have no one to assist them. As one female interviewee reported,

> "...Being told look for a treatment partner is a problem which deny some patients from treatment or delay them on initiating treatment. It was very difficult for me to get a treatment partner because I trust no one at home until when I got one I trusted..."

4. 3 To explore perceptions that SHDEPHA+ members had before they were initiated on treatment

The results showed that all interviewed perceived well and valued this programme of antiretroviral therapy services provision because they said that if it was not due to these drugs they would not have been present today. They said now doing their daily activities as usual, the numbers of death in their community observed in the past have been

decreased and the ailments they were getting were no longer present. A 36 year old female respondent said,

> "...I believe that antiretroviral drugs have helped us a lot ... and we thank the government because previously when services was not free very few were accessible to these medication and you know how it was, but now we are alive, and death toll has gone down compared to the past; thank God for these medication we would have been finished without these drugs ..."

Some interviewees said that antiretroviral drugs cause hunger and so the government should find a way of helping those who can not afford food at times when they are weak as some have been affected by these due to lack of food. For instance, a 38 year old female respondent narrated,

> "...Some patients have lost their lives after taking these drugs without food, two of my friends died because they had no one to give them food..."

Results have shown that some ARVs have very bad side effects to the extent that they cause bad reputation of these drugs for causing side effects to patients. They said there was a drug which was introduced which caused some individuals to lose muscles in the face, buttocks and hips and increase in the size of the tummy and breasts. They claimed that even the strength of this medicine is questionable

because it does not bring relief as the former drug. A 38 year old female witnessed that,

> "...My friend was affected with this new drug which is red in colour compared to the former white in colour...she wasted buttocks, hips and increased size of the breast. Also these drugs have no effect on fungus..."

But they said that not all who take drugs are affected therefore counselors should be keen during counseling to patients prior starting drugs on the side effects of these drugs.

Results also show that antiretroviral drugs was not the cause of increased libido (increased sexual arousal), they said it is due to the return to normal body functioning of the patients. One female interviewee aged 42 years reported,

> "... These are individual feelings...when you are sick how can you think about sex? When you start taking drugs your health goes back to normal as any body else and sexual feelings as well...because when I was still very sick lying on bed how could I think of sex at stage but when I started taking ARVs my health is equivalent to any body else and my sexual feelings have returned to normal ..."

The results showed that there were concerns from the community that antiretroviral drugs were not good. Some of the negatives pointed out were, they are poisonous, they could

cause cancer when they accumulate in the stomach, and they hasten individuals who took them to death. For instance, a 30 year old female informant reported,

> "…There were rumours from the community that these drugs may kill or cause cancer when they accumulate in the abdomen this caused some patients to use local herbs and GNLD, but since I started taking these drugs I have not observed what I heard previously… "

GNLD is a 40+ year old World wide corporation manufacturing nutritive supplements. Interviewees said that individual who held this in the community were the ones who did not want to be tested and did it for the purpose of discouraging people taking these drugs or those who intended to start taking ARVs.

Results showed that misperceptions of the disease and antiretroviral therapy were held in the community. They manifest as these drugs are spurious that is why some doctors who are sick did not take them, these drugs have been brought to kill people, neighbours and relatives telling patients taking the drugs that they are wasting time, the disease is caused by witchcraft and others reported that the disease had been present immemorial and was called Kunyalanyala (meaning a person bewitch you and you waste just like an AIDS patient until you die), this was narrated by a female respondent aged 37 years,

> "…People claim that this disease was there in the past known as wasting disease; you were bewitched with a person and wasted until you died …, things like these

beliefs cause some patients delay seeking medical attention as they seek first alternative arm of treatment..."

Interviewees reported that these misperceptions are there because the community lack knowledge of the disease and antiretroviral therapy and they said advertisements given about the disease and ART do not reach the target population. A 44 year old man asserted that,

> "...We who live in squatter streets do not know AIDS ... because social marketing done did not reach target audiences ... because they are used in listening sessions concerned with comedies and game sessions,... for instance, when the wife of a local brew seller died with all symptoms of AIDS, they said she was bewitched. Her husband married four wives after her death ... and worse the customers of this local brew seller were doing sex with all the wives of this man after he was drunk in his own house lastly that man died as well...",

4.4 To explore whether late uptake of antiretroviral therapy was related to inaccessibility of therapy

The results show that factors responsible for late uptake of antiretroviral therapy were government policy on antiretroviral therapy programme, hesitance of testing for HIV of

the community, poor knowledge of the community on HIV and AIDS, poor quality of services on antiretroviral therapy offered by the public health sector and its partners, poor knowledge on drug side effects, cultural barriers and beliefs, denial, discrimination and stigma.

The government policy on antiretroviral therapy services initially was not provided free of charge which included drugs and investigations prior to starting of medication. Some informants reported that they were not able to buy the drugs because such drugs are available in private pharmacies at very high price. They said that was a reason for some not seeing a need to test. One male respondent aged 37 years said,

> "…Government policy delayed free antiretroviral drugs which hindered poor people from access … because formerly even checking CD4 counts was very costly leave alone the drugs, now drugs are free of charge therefore educating people is important so that they can test early and start medication early…"

A 42 year old female informant asserted,

> "…. Formerly when there were no free antiretroviral drugs people did not see why they have to test because they said even if you tested what would you benefit ...you will die just like a person who has not tested …"

Results revealed that hesitance of the community to voluntarily test are a problem. As such, people feared to be tested because they anticipated what would happen if the results would be positive. Some tested but were afraid to get their results. A 24 year old female respondent confessed that,

> "...Testing is a frightening thing...I tested for the first time ...ran away without receiving the results...but I had no choice after health deteriorated I tested again and received the results ..."

Results showed that knowledge on HIV and AIDS of informants determined health seeking behavior. They said misperception of the causality of the disease delayed some informants seeking formal medical care, wasted time to traditional healers, perceived they have been bewitched, and some reported that traditional healers told them were suffering from evil spirits. They therefore wasted time when they were attending these therapies. A female respondent aged 30 years reported that,

> "...When my husband died suffering from chronic illnesses, people said he was bewitched from his job mates... when I also started suffering I did not know that I was HIV positive. I thought I was bewitched as well ... my symptoms were just like those of my late husband..."

Some interviewees reported that they delayed antiretroviral use from the rumours they had heard about the drugs. They said it was claimed that drugs cause death as soon as you start taking them, they caused body swelling, rashes and they would cause change in

their life styles and live unhappy life for example they would not be able to drink alcohol or do sex. But they were puzzled after they started taking drugs and their health became better than before therapy. One female respondent aged 30 years said,

> "…The community does not have knowledge of antiretroviral drugs and the side effects… that is why they claimed that they would cause sudden death after using them , cause life style changes like denying you alcohol and sex … I was also worried by these rumours until I started taking these drugs…"

Poor quality of services offered by the public antiretroviral therapy services and the private sector was reported as one barrier to early uptake of antiretroviral therapy because of poor service provider and client interactions. Some informants said that after they were tested they were left without clear advice as what should be done after that testing and CD4 counts. A 44 year old female informant witnessed that,

> "…Because of poor counseling which I got in the first time after testing delayed me start therapy at very low CD4 counts … because my initial CD4 counts was 1200 and I started therapy at 76 CD4 counts…"

Results show that some doctors delay patients' therapy for not telling them the truth from the beginning. This was reported by informants saying that they visited health facilities

several times but was not told their problem. They said each time was prescribed a drug until when symptoms started to manifest. A female respondent aged 45 years asserted,

> "…I was tested in 2000 initially but not told the truth until 2006 when I was tested again and told the truth that I was infected with HIV and this testing was incidental because I went there to accompany my daughter who was sick..."

She said if it was not due to my daughter I would have died without knowing what my problem was. Another female respondent aged 43 years said that,

> "… I thought doctors contributed to my late use of antiretroviral drugs because I attended several times to health facilities to seek medical care but each time prescribed a drug only until when my health was poor..."

The results show that some non government organizations offering care and treatment services for people living with HIV and AIDS compounded the effect of late uptake of antiretroviral. It was reported that these organizations test patients and not start them on therapy even if they are eligible to start therapy. For instance, two informants were left their CD4 Counts to drop from initial testing to very low levels. The first was left and her CD4 counts dropped from 150 to 28 and the second from 200 to 68 all without being started on treatment. A 34 year old female reported,

"…I was left without clear reason my CD4 counts to drop from 150 to 28…. and my condition was worse when I was started on therapy. They told me that despite my CD4 counts being low I was still strong and their was no need to start therapy…."

Results show that denial, stigma and fear of discrimination were shown as limiting factors to start early therapy. Some informants reported that they tested several times but it was hard for them to accept the result until when there health worsened. A female respondent aged 31 years asserted that,

"… Lack of confidence and acceptance of the problem caused me to deny that I was infected with HIV…despite the fact that I knew my husband died due to AIDS in 2002… but I accepted my results in 2005 when my health was worse and that was after testing three times..."

Some informants reported that they feared testing of HIV due to fear of the disease and being discriminated. A 43 year old female said,

"…I really feared the disease and discrimination… because my husband died in 2002 due to HIV/AIDS but I thought after several months I would be dead … but days passed until 2005 when I decided to be tested…"

Some informants reported that fear of being stigmatized kept away some informants from therapy. They said if seen taking the drugs they would be looked as sinners in the community, as their problem was caused from their deviant behaviours. A 44 year old male informant asserted,

> "...I did not tested because of fearing being stigmatized ... being seen that I got the disease from prostitution ... because people do not know that you can have the disease not from what is believed as deviant behaviour...".

4.5 To explore opinions of people living with HIV/AIDS in SHDEPHA+ on early use of antiretroviral therapy services.

The results of all interviewees favoured efforts enabling each eligible patient start antiretroviral therapy services early. They said antiretroviral drugs have enabled them to be there at that moment of interview, if all individuals would start therapy at right time would reduce dependency of patients and the number of death. Some informants said they were weak to the extent that they could not turn back without falling down. Some informants wondered why in this country patients start therapy at very low CD4 counts compared to the West. A male respondent aged 47 years said,

> "... I heard from BBC radio station that patients in the west start therapy at 350 CD4 counts. Why are we left until we are very weak? Many have died

from drug strength due to weakness because they start therapy when they are very weak to withstand the medication…"

They also said that some of non governmental organizations offering care and treatment of people living with HIV and AIDS should be stopped delaying patients checking their CD4 counts and starting them on therapy because physically they are still strong but biochemically they are eligible for medication. They said you test positive they did not check your CD4 counts until they saw you start loosing weight.

Informants suggested that quality of care offered by clinics offering testing and provision of drugs should be improved. Furthermore, they appealed that investigations for patients who have tested positive should be free of charge and equipments for checking CD4 counts should be available. A female respondent aged 31 years said,

> "...Investigations for positive patients for HIV and AIDS should be free of charge because sometimes this is a barrier to start treatment… I was positive but I had no money for investigations preparing me to start therapy … I waited until I got money for those investigations…"

Informants said that because AIDS is stigmatized in the community the government should increase sensitization meetings to the community as often as possible, so that the public understands the disease and the benefits of early testing and starting treatment early. They said because people will be knowledgeable about the disease and treatment

will lead to perceptions, beliefs, culture and attitude change. They said for this to be successful should be pioneered with PLHA.A 46 year old male respondent said,

> "...This disease is stigmatized in the community... the government should enhance health education, meetings in the community as often as possible...people living with HIV and AIDS should be involved in order to be successful..."

Informants said this was important because feared confrontation with their neighbours who had all symptoms of AIDS. They said if you dared advising any patient you suspect is suffering from AIDS you would be insulted. An elderly female respondent said,

> "... Sensitization meetings in the community are important... because even if you show a person the ARV drugs you are using he, or she may not trust you and that if you advise a person that you are suspecting that he or she has AIDS you will be insulted ... so it will be better if all these are addressed at public meetings...."

Another suggestion offered by informants was that each individual attending a health facility should be tested and given results and left to decide what to do. A female respondent aged 29 years said,

"...I think all those who attend hospital should be tested for HIV and be given results and left to decide what to do... Prevention of maternal to child transmission of HIV/AIDS helps a lot women ...because they are being tested relatively early compared to males... that is why males attend hospitals at very late stage and advanced disease..."

Other opinions given were to use organizations of people living with HIV and AIDS, visiting patients at their homes and educating them the importance of testing for HIV. In addition, the government should use street, village, ward, division and district leaders to do sensitization to the general community to see the importance of early testing which will facilitate early use of antiretroviral and testing of HIV/AIDS to be conducted within ten-cell leaders but the results be kept confidential between the clients and the service provider. A male respondent aged 44 years said,

"....Testing should be conducted within ten cell leaders... and results should be kept confidential between the client and the service provider... I hope this would be successive because the number of people infected with HIV/AIDS is big but people do not want to test..."

4.7 SUMMARY OF FINDINGS

Study findings have shown that awareness of antiretroviral therapy services among informants were poor, revealed by finding that most of the informants obtained the information when were seeking medical treatment from health facilities. Health messages about seeking for VCT, Care and Treatment in the current way might not be reaching the

target population because few reported obtained this information from radio. Lack of awareness might have been the cause of late use of ARVs to these informants.

Findings have shown that informants started therapy below the recommended CD4 counts by the national guideline for managing HIV/AIDS. The reasons were late presentation of these informants and partly due to health sector. Some medical doctors did not told informants their sero-status early so they can decide what to do. Some institutions delayed informants to start therapy by practicing contrary to the MoH & SW guidelines for managing HIV/AIDS.

Findings showed that informants were embedded into negative perception towards ART before they started therapy. These included exaggeration of drug side effects, unsatisfaction with ART efficacy, not believing that HIV is caused by human immunodeficiency virus .These perceptions changed when informants were started on therapy. Informants said negative perceptions are held because they had poor knowledge towards HIV/AIDS.

Findings showed that reasons mentioned for late use of ART by informants were former government policy on ART did not provide these services free of charge, hesitance of informants to test HIV and accept results, lack of knowledge on HIV/AIDS and ART, Some institutions practicing contrary to MoH & SW guidelines for management of HIV/AIDS and some mentioned denial, discrimination and stigma. All these were embedded within the cultural background of informants.

Findings showed that informants appealed the government to change policy on the level of CD4 counts patients are being initiated ART; to be 350 CD4 counts compared to the Western world. Nevertheless, investigations to sero-positive patients be free of charge. Informants said every patient attending health facilities should be screened for HIV to increase detection coverage and give appropriate counseling to these patients, so that they get an opportunity start ART early.

Informants suggested the government to sensitize the community through meetings from house hold level, hamlet, and village level to national level in order to change the negative perceptions embedded within the society as these have been seen as source of some informants delay ART, therefore the community change their health seeking behaviour.

CHAPTER: 5 DISCUSSION, SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.0 INTRODUCTION

This chapter starts by discussing the findings of the study. The chapter then presents conclusion and recommendations from the study. The presentation is organized into three parts. The first part is the discussion about the extent to which SHDEPHA+ members were aware of antiretroviral therapy services before they were initiated on treatment; time lapsed between an individual knowing sero positive status and initiating ART among SHDEPHA+ members on ARVs; perceptions that SHDEPHA+ members had before they were initiated on treatment; either late uptake of ART were associated with unavailability of therapy to PLHA and opinions of PLHA in SHDEPHA+ on ART services. The second part is the conclusion; and the last part consists of recommendations emanating from the findings.

Before proceeding with study findings discussion, it is important to congratulate the President of the United Republic of Tanzania for launching a campaign in 14 July, 2007 which ended in 30 April, 2008.This campaign was concerned in encouraging the general community to know their status for doing voluntary counseling and testing for HIV/AIDS and take their role in the prevention of HIV/AIDS.

This campaign has shown that the trend of the epidemic is going down with the current strategies in fighting the epidemic. For instance, in Urambo district Tabora region previous prevalence of HIV/AIDS was above 12 percent basing from VCT and blood donors HIV/AIDS screening datas.Prevalence of HIV/AIDS from the recent ended

presidential campaign has been shown to be 2.7 percent. Therefore the president concern has enabled to get the actual prevalence of HIV/AIDS in the community as well.

5.1 DISCUSSION

5.1.1 THE EXTENT TO WHICH SHDEPHA+ MEMBERS WERE AWARE OF ANTIRETROVIRAL THERAPY SERVICES AVAILABILITY BEFORE THEY STARTED THERAPY

The findings showed that participants became aware of antiretroviral therapy services when they visited health facilities whether they were publicly or privately owned. Some got the information about ARVs from relatives and some heard from the radio. Those who were informed by their relatives it was due to their presenting AIDS symptoms. From this study more than 60 percent of the interviewees became aware of antiretroviral therapy services when they visited a health facility as they were sick. The common complaints were chronic fever, tuberculosis, herpes zoster and other AIDS defining illnesses. This is consistent with findings of the study which was done in the United Kingdom which showed that most of the patients who were on ART services became aware of their status due to a medical condition which caused them to visit a health facility (Edwin, 2007).

The results have shown that the community is not aware of care and treatment services because they knew the availability of ART services when they visited a health facility. This especially existed in villages as they held once you suffer HIV/AIDS there is no room for any help. Those who heard the information from radio did not believe until

clarification was obtained from a second source. This shows the importance of scrutinizing the media to be used before communicating information which is sensitive. For sensitive information, the best channel is face to face communication.

These findings are consistent with a study done in South Africa among PLHA where it was found out that awareness towards ART services was generally poor. Antiretroviral drugs were not perceived as new, but one of many alternative therapies for HIV and AIDS. Respondents had more detailed knowledge of indications, effects and how to access alternative treatments which is bolstered by the active promotion and legitimization of alternative treatments. Many expressed a lack of excitement about the introduction of ART and little change in their attitudes concerning the epidemic (Chopra et al., 2006).

Some participants visited health facilities several times for various medical reasons they were not told the truth by doctors. Such behaviour caused most patients to be diagnosed late and delay starting treatment. For antiretroviral therapy programme to be successive, doctors should counsel patients early if they suspect that they have HIV/AIDS and screen patients at earlier stage of the disease.

Results also showed that some organizations providing care and treatment for PLHA cause some delays for some patients in starting taking ARVs. They tested people for HIV status and diagnosed them positive but for unknown reasons some of them were delayed therapy until their condition became worse. It is important for the health sector to do

regular supervision to these facilities because they are not adhering to guidelines of the Ministry of Health and Social Welfare.

Despite the awareness of HIV and AIDS in the general population is estimated to be above 90 percent (THIS, 2003/2004), awareness of antiretroviral therapy services have been shown to be poor. Accordingly, intentional sensitization should be conducted by the government involving PLHA through public meetings starting from village level to national level. This has been suggested from findings because other modalities of mass media have shown failure.

5.1.2 TIME LAPSED FROM AN INDIVIDUAL KNOWING SERO POSITIVE STATUS AND INITIATING ART AMONG SHDEPHA+ MEMBERS

Findings have shown that delayment in initiating ARVs among interviews was not a factor but was due to their late presentation. The quality of life improvement depends much on the level of CD4 counts when an individual start ART. Because these interviewees started ART late most of them experienced adverse effects of the medication. This is consistent with a study done in India among 159 patients who initiated treatment late at CD4 lymphocyte count below 50 cells per cubic milliliter, showed that 22 patients equivalent to 13.8 percent had severe adverse effects and were discontinued from treatment(Sungkanupark et al.,2005).

Findings have shown that medical profession has been blamed for not telling patients the truth early so that they can make their decision early to start therapy. Some informants said they attended health facilities several times before they developed symptoms but

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they were not told that they might be having HIV/AIDS. Informants appealed that medical profession should change this behaviour as it is costing much to patients.

Findings showed that some institutions providing ART services for research purposes have not been fair when it happens that the informant fall outside their eligibility parameters. Some informants said they were left without appropriate advice to alternative source of care. As a result their conditions continued to deteriorate. Indeed, this has been impingement to early ARVs use. Informants suggested that the MoH & SW should constantly monitor practicing of these institutions.

Findings have shown that some non governmental organizations providing care and treatment to PLHA have been blamed for not providing care according to the MoH & SW guidelines for managing HIV and AIDS. These organizations start patient on ARVs therapy according to their own principles which are not formal. Some informants said their sero-status were positive and CD4 counts within eligibility interval but they were not started on therapy .They were told that they have to wait until they start loosing wait. Some informants said they were delayed until they were bedridden and were thus started on therapy at late stage. Informants suggested that the government should oversee the practice of these organizations for the good sake of its people.

The government of Tanzania health policy says that it will provide quality, accessible, equitable health care especially to the marginalized group (MoH, 2004), this policy was not considered when ART services were introduced into this country. Antiretroviral

drugs, HIV testing and CD4 counts determination were not provided free of charge. Findings have shown that yet this is a bottleneck for some patients. These findings are consistent with studies which were done in Latin America and Kisesa in Mwanza, Tanzania where it was shown that patients were unable to access therapy due to cost involved in these services (Mshana et al., 2006; Tantivess et al., 2006).

Findings have shown that interviewees sought antiretroviral therapy services involuntarily because most of them attended HIV testing for medical reasons such as chronic illness, opportunistic infections, tuberculosis, herpes zoster, death of a partner and others. These findings show that informants were not sensitized on the importance of voluntary testing before the disease became overt, and this was the cause of delaying in using. These findings are consistent with an audit study which was done in United Kingdom where patients on antiretroviral therapy were audited and it was found out that they were recruited into ARVs therapy below the country guideline for treating HIV and AIDS and it was also found out that most of them sought treatment due to medical reasons such as renal failure, stroke, pregnancy and others (Edwin, 2007).

Findings showed that informants are concerned with some conditions prior to admission into ART services. For instance, patients are required to bring a treatment partner, which has been a thorn to some patients. Some do not have those persons or they have no one they trust. This has been seen as a barrier for some patients to access early therapy, and suggested that this should be changed.

Some informants blamed that a certain antiretroviral drug which was introduced recently as first line has been blamed as responsible for severe side effects. These side effects might be attributed by the drug or because these patients started therapy late at low CD4 counts. These findings are consistent with a study done to 159 patients who started ARVs at CD4 counts below 50 cells where 22 (13.8%) were discontinued from therapy due to severe side effects (SungKanuparch et al., 2005). Therefore it is important to sensitize our patients start therapy early to avoid the negative effects of the drugs. This will minimize the bad reputation to these drugs and motivate other patients use them.

5.1.3 PERCEPTIONS THAT SHDEPHA+ MEMBERS HAD BEFORE INITIATED ON ARVs THERAPY

Interviewees perceptions, beliefs and attitudes were negative towards the disease, its therapy and sensitization towards testing for HIV before were introduced into ART. This may be taken as a reflection to what is existing into our society.

Findings consistently showed that informants changed their perception, beliefs and attitudes towards the disease, therapy and testing for HIV after being introduced into ART.

Findings show that informants perceived that the cause of AIDS is not human immunodeficiency virus but something else. Some perceived that it's due to supernatural powers and some said it is due to witchcraft as they said this disease has been present in

the community for a very long time known as "kunyalanyala" (meaning a disease secondary to witchcraft where an individual continuously wastes until he or she dies). The informants also held that AIDS has no cure if one gets it he or she has wait to die, that was a reason for not testing and looking ARV drugs for some informants. These findings are consistent with a report given by the Tanzania NACP which showed that these perceptions affected ART roll out, for instance the target was to enroll 500,000 patients by 2008, however till September 2006 when there were only 49,915 patients on ARV (NACP, 2004; PlusNews, 2007).

Findings have shown that informants held negative perception towards ARV drugs. They believed that ARVs were brought to hasten killing AIDS patients so that they can no more infect other people. Also it was said these drugs are poisonous when they accumulate in the stomach causing cancer. Other informants were discouraged to use ARVs being told that they are wasting their time because these drugs are not effective, they are spurious that is why doctors who are infected with HIV are not using them.

Antiretroviral drugs have been associated with side effects especially to those patients who begin therapy at low CD4 counts, that is, 50 cells (Marin et al., 2004; Stoekle et al., 2006; Mshana et al., 2006). Also it is difficult to predict which patient will develop side effects, but in this study these perceptions were generalized and exaggerated to discourage informants starting therapy. It was also shown that negative attitude among AIDS patients towards antiretroviral therapy affected early health seeking behaviour causing delays in ARV drug use (Schrimshaw et al., 2005).

Findings showed that informants before were on ARV therapy feared to start therapy because of interfering their life styles. It was held that when one starts this medication he or she will miss alcohol and also sex and said because these are enjoyed by all, some decided not to start ARV drug therapy. These findings are consistent with a study which was done in Latin America among AIDS patients on ARV drug therapy where it was found that some patients interrupted therapy because of the changes in their life style (Nischal et al., 2005). These findings points on the importance of proper counseling before starting ARV therapy to patients.

Findings have shown that informants perceived themselves to be at low risk to contract HIV, as result they did not see a need to test. This perception caused late detection of the disease and this caused denial of results when an informant was found to have positive status for HIV/AIDS. These findings are consistent with a study which was done in Kunming city in China among injecting drug users found out that they perceived themselves not have risks for HIV and AIDS. Results revealed that 32 percent of the interviewed had risks for HIV because were sharing injecting needles and 65.3 percent of respondent had unprotected sex with casual sex workers (Kobusingye, 2004).

Findings consistently showed that informants held these perceptions because of lack of appropriate knowledge of HIV/AIDS and antiretroviral therapy. Suggestions given were that; there is a need to give appropriate knowledge about HIV/AIDS to community, so that negative perceptions can be minimized. This is important so that people can test for

HIV early and start therapy, because this is an important intervention against spread of HIV and AIDS (THIS, 2003/2004).

Findings have shown that after informants were started on antiretroviral therapy their perceptions about what they knew about HIV/AIDS and ART changed absolutely, now were positive towards antiretroviral therapy and early testing for HIV. These findings are consistent with a study done in Australia among patients on ART where it was shown that positive attitude towards ART was associated with use of medication (Kanouse et al., 1996).

Findings showed that informants thank the government for free antiretroviral therapy to patients and they asked the government to start providing free investigations preparing them for ARV therapy. Because some patients did not afford the costs for these investigations, study done by Tantivess et al., (2006) showed that it is important for the government to provide ART services free to ensure accessibility. Other study done in Kisesa district Mwanza, Tanzania among PLHA showed that accessibility to ART was affected by poverty (Mshana et al., 2006).

Findings showed that informants health progressively returned to normal as they started ARV therapy, their working capacity returned to normal, absenteeism from work declined, number of death declined and their ability were equivalent to normal individuals and denied the rumours that ARVs increase feelings of sex but it is due to the body recovering to normal functioning. These findings have been supported by other

studies done on PLHA who are using ARVs drugs which showed that there were dramatic decline of opportunistic infections hence HIV-related mortality, patients regained close to normal quality of life, working burden of the health sector declined due to reduction of hospitalization (Detels et al., 1998; Dominick et al., 2004; Pallela et al., 1998).

Findings suggest that there is a need to sensitize people to change the way they perceive HIV and AIDS. HIV testing and ART through health education and community meetings from village to national level because what was held by these informants before starting ART might also be existing in the general population.

5.1.4 REASONS FOR LATE UPTAKE OF ARVs

Findings showed that reasons mentioned as were cause for informants' late use of antiretroviral therapy have almost been discussed in preceding discussions. Other reasons responsible were the government health policy on ART provision, attitudes of informants towards HIV testing, knowledge of informants on HIV/AIDS as disease and ART, the quality of services provided by the health sector, cultural background of informants, denial, discrimination and stigma.

Findings showed that the government health policy on ART services when it was introduced for the first time was not provided free. Initially testing for HIV was done in government facilities while drugs sold by private pharmacies.CD4 cells determination was not done free of charge. These were seen by informants as a barrier to start therapy

for patients who sought these services in early years of 2000.Informants suggested that currently some patients could not afford investigations done prior starting ART and asked the government to consider providing them free of charge to sero-positive patients. Because these patients are marginalized, therefore providing free services could improve access (Tantivess et al., 2006).

Findings showed that informants delayed testing for HIV for fearing embedded cultural beliefs, perceptions, and attitudes in their community. These findings are consistent with studies which showed these factors affected ART roll out (NACP., 2004; PlusNews., 2007). All these were negative towards ART therapy and the disease, and these negative perceptions have been associated with poor utilization of ART services (Schrimshaw et al., 2005).Positive attitude towards ART has been shown influence utilization of these services as it was showed by study done in Australia (Kanouse et al., 1996).

Findings showed that informants held these beliefs before were initiated on therapy but changed their perception upon starting therapy. This shows that their knowledge about the disease, ART and importance of early testing for HIV was lacking. Lack of knowledge on the importance of ART has been shown to impair ART roll out by a study which was done in Kisesa district in Mwanza, Tanzania (Mshana et al., 2006).

Findings have also shown that non governmental organizations should be monitored regularly on their practice. These organizations were shown to delay patients either in determining their CD4 counts or starting them ARV therapy. These patients were left till

their immune status declined to low levels predisposing them to risk of developing side effects.

Findings showed that denial, fear of being discriminated and stigma kept some informants away from starting ART therapy. Some informants considered themselves to be at a low risk of contracting HIV/AIDS. When tested were found positive for HIV but rejected to accept the results. These findings are consistent with study done in Kunming city in China among injecting drug users where results showed that 32 percent of those perceived to have low risk for HIV interview revealed had shared injecting needles and 65.3 percent of these had unprotected sex with casual sex workers. And 69.3 percent of respondents said stigma and discrimination kept them away from testing (Kobusingye, 2004).

5.1.5 OPINIONS OF SHDEPHA+ MEMBERS USING ART SERVICES

Findings have shown that after informants were being started on ART their attitude were positive towards ART programme to the extent that some suggested that HIV testing should be made mandatory to whoever seek service to any health facility. They said this strategy might increase the number of people testing for HIV as well detect patient at earlier stage of the disease like what is being done among pregnant women during antenatal clinic visits. This might start patients early to ART. These findings are consistent with study done in Gauteng province in South Africa where it was found out that linking antenatal clinic and care and treatment clinic facilitated early initiation of patients to ART (Van der Merwe et al., 2006).

Some informants have been concerned about the level patients are started on therapy. They said at that level of CD4 counts most patients are weak and some could not withstand strength of the drugs. Suggested that government should consider revising this level to be equivalent to Western World where patients are being initiated therapy at 350 CD4 counts (Edwin, 2007).

Results suggested that the Ministry of Health and Social Welfare should keep an eye on those institutions which are operating against Ministry of Health and Social Welfare guidelines for managing HIV/AIDS. Also the MoH & SW should ensure good quality of health care is provided to patients by ensuring all requirements needed are met. This might attract ART services utilization. The government has been requested to consider providing free investigations for patients, who are sero-positive, provide food to patients who can not afford especially at early stages of therapy when patients are weak.

Suggestions have been given for the government to increase sensitization to the public because perceived beliefs are still embedded into the society. Sensitization should be done from house hold, hamlet, village, and subward level to national level through community meetings, dramas preferably with PLHA.

5.2 CONCLUSION

Awareness of the availability of ART services is still poor into our society, there is a need to change the way we are delivering health messages it seems they are not reaching the target population.

Perceptions held into our society are responsible for causing delays of patients to access therapy, and these perceptions have rooted because of knowledge gap in our society about HIV/AIDS and ART. There is need to sensitize our community by providing them knowledge by employing the best strategies of delivering them.

We suggest consideration of policy changes on the level of CD4 counts patients are being started on therapy, because most of our patients start therapy at low CD4 counts. Therefore there is need to consider raising level of CD4 counts equivalent to the Western world. Also, the government should make consideration of providing free work up investigations and food especially during the early stages of therapy when most of AIDS patients are dependent.

Modification of the current approach of delivering ART services might improve access to these services and mitigate the impact of HIV/AIDS. Things like treatment partner should be reconsidered again if really are necessary as preconditions of starting therapy to an individual who has consented to that therapy.

5.3 RECOMMENDATIONS

5.3.1 Findings have shown that perceptions upheld against ART are due to lack of knowledge on HIV/AIDS and ARVs therefore health education should be enhanced to the general community through sensitization meetings so that the community becomes knowledgeable on the importance of these services

5.3.2 Organizations involved in provision of ART services should be monitored regularly and closely to control what is happening now in these organizations. These organizations some are not adhering to the Ministry of Health and Social Welfare guidelines for managing HIV and AIDS. This has sometimes caused delays to start ART.

5.3.3 Advocacy to the community should be done on the efficacy of ART services preferably with PLHA. Because findings have shown that negative perceptions are embedded because the society lacks appropriate information on HIV/AIDS and ART services.

5.3.4 Findings have shown that most of our patients seek ART services at late stage of the disease therefore Policy changes should be considered on the level of CD4 counts where patients are being started on ARVs therapy, from 200 to 350 cells and investigations to sero-positive patients should be free of charge.

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