

**Understanding the determinants of adherence
and the evolving challenges to HAART among
people receiving free antiretroviral drugs at the
medical centre of Pissy in Ouagadougou,
Burkina Faso**

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LIST OF ACCRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Antiretroviral Medicines
CBOs	Community Base Organizations
CSLS	Cadre Strategic de Lutte contre le SIDA
FBO	Faith Based Organization
GDP	Gross Domestic Product
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immuno Deficiency Virus
KIT	Royal Tropical Institute
MoH	Ministry of Health
MSF	Médecins Sans Frontière
NGOs	Non-Governmental Organizations
OPD	Out Patient Department
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission (of HIV)
PRSP	Poverty Reduction Strategy Papers
UNAIDS	United Nations Joint Program on AIDS
UNDP	United Nations Development Program
UNGASS	United Nations General Assembly Special Session
WHO	World Health Organization
CMA	Centre Medical avec Antenne Chirurgical

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Figure 1: Conceptual framework

Table 1: Methods of measuring adherence

ABSTRACT

Title: Understanding the determinants of adherence and the evolving challenges to adherence to HAART among people receiving free Antiretroviral drugs at the Medical Centre of Pissy (CMA) in Ouagadougou, Burkina Faso.

Objectives: the purpose of this study is to elicit the evolving challenges to antiretroviral treatment at the CMA of Pissy, in Ouagadougou in order to generate appropriate recommendations on adherence enhancing interventions.

Methods: A qualitative exploratory research approach was conducted using a series of three individual semi-structured interviews with 16 patients receiving free ARV for at least three years at the CMA of Pissy, which provides free antiretroviral to a large volume of patients in Burkina Faso. A conceptual framework on ambulatory treatment was used to develop the topic guide and to analyse the interview transcripts (Uquhart and Vrijens). The purposive sample was selected based on gender and on length of treatment. Participants were asked to describe their life trajectories, how much the antiretroviral treatment fits with their everyday lives, the evolving barriers to as well as the strategies they used to enhance adherence.

Findings: Major factors that influence adherence negatively included illiteracy, transportation costs, hunger, fear of disclosure, stigma and discrimination. Facilitating factors included acceptance of the disease, feeling healthy, family and community support, self-support group, living for someone. Religion plays a dual role as barrier and facilitator to adherence. Coping strategies included secrecy, pills carrying and disease or medicines assimilation.

Conclusion: People living with HAART need an enabling environment and our findings call for interventions at individual, family, society and organization levels. The findings highlight the importance of close environment's support, treatment literacy, improved access to ART related ART services, which should be strengthened.

Key words: adherence, antiretroviral viral therapy, determinants, HIV, AIDS, Burkina Faso

Introduction

The 11th International AIDS conference held in Vancouver in 1996 was generally seen as the most hopeful and optimistic AIDS conference. Indeed, this meeting was marked by considerable promising results with anti-HIV drugs combination therapy adoption. However, at the 12th conference at Geneva in 1998, the Executive Director of UNAIDS already came up with some obstacles related to antiretroviral therapy (ART) inclusive of poor patient adherence to complex treatment regimens (amfAR, 2002).

In Burkina Faso, the first ARVs (antiretroviral medicines) available for purchase in private pharmacies were found in 1996. Until 1999, the country did not have a programme to expand and rationalize access to antiretroviral therapy (Nguyen, 2003). Like many other Sub-Saharan African countries with not yet well-defined or weak mechanisms for drugs procurement and distribution at this time, drug interruptions were more likely to happen in Burkina Faso. Also at this time, there was no system in place to monitor adherence or drugs' efficacy. This was coined 'antiretroviral anarchy' by Harries (2001).

Thus, in 1999, the Burkinabe government decided to regulate the procurement of ARVs by simultaneously licensing these drugs and limiting authorization to import ARV to a para-statal company (Nguyen, 2003). Burkina Faso in collaboration with its international and local partners aimed at up scaling ART. The CMA of Pissy district (CMA of Pissy) in Ouagadougou health region was among the beneficiaries of the increased efforts to scale up ARV provision. Indeed, an ART clinic was opened at the CMA of Pissy in 2002 with the support of Médecins Sans Frontière (MSF).

ART has transformed the HIV infection into a treatable and chronic condition. However, the need to continue treatment for decades rather than years, calls for a long-term perspective to treatment. Adherence to the regimen is essential for successful treatment (Nischal, 2005).

Adhere over time remains a challenge for people on HAART. Among patients on ART at the CMA of Pissy, some were on treatment for over three years.

Pissy district management team and MSF aim at enhancing adherence by decentralizing ART to health centre levels, which would be a première in Burkina Faso. Another strategy is to strengthen patients' autonomy with regard to the management of their treatment. I served as a Medical Doctor in this facility and the purpose of this thesis was to better understand patients' environment, facilitating and inhibiting factors to adherence to ART from the patients' perspective. Thus, this thesis will contribute to define better strategies, which will enhance adherence to ART.

1.0 Background/Literature Review

1.1 Background

1.1.1 Socio-economic and demographic situation

Burkina Faso is a landlocked country in the middle of West Africa. It is surrounded by six (6) countries: Mali to the north, Niger to the east, Benin to the south east, Togo and Ghana to the south and Ivory Coast to the southwest (see *Appendix 1*).

With a population of 13, 6 million, the age structure shows the predominance of youth, with 55% of the total population and the predominance of female (52%) as well. Burkina Faso is one of the poorest countries in the world. Indeed, according to the Human Development Report 2007, its GDP per capita was estimated at 1,213 international US\$. The illiteracy rate is still high – 76% (UNDP 2007)

A combination of drought, overgrazing, wildfire has contributed to high rate of desertification and deforestation. This offers a fragile basis for agriculture and the livestock industry. As a result of this situation, large proportions of young people in the labour force migrate to the cities and neighboring countries looking for work.

Formerly a French colony, the Republic of Upper Volta was in 1984 renamed Burkina Faso, which means the 'country of men of integrity'. There are many sayings on integrity and honor, such as 'Burkin saka kuum zoe yende' which means that the people of Burkina Faso prefer to die than being ashamed; 'scare shame'; 'refuse shame'. The Burkinabe (inhabitant of Burkina Faso) is characterized by its hospitality, solidarity and dignity.

Burkina Faso has diverse ethnic groups (60) and cultural compositions that are reflected by different cultural practices. However, a common feature of traditional life is the strong communal and family support system such as the extended family system (Burkina Faso, 2003).

With the urbanization and the consequent rural-urban migration, these systems are breaking down resulting in the development of nuclear families. The Burkina people are very religious. The main religions are Traditional, Islam and Christian.

1.1.2 HIV/AIDS epidemic and the National Response in Burkina Faso

According to UNAIDS, Burkina Faso remains a country with a generalized epidemic of HIV/AIDS. Indeed, the Demographic Health Survey (2003) found an overall prevalence of 1.9% with higher rates in urban (3.1%) than in rural areas (1.0%). According to the same source, women are more infected (3.4%) than men (2.7%). UNAIDS estimated absolute number of 100 000 for orphans, 110 000 for PLHIV, while the deaths was 11 000 in 2007 (UNAIDS/WHO, 2008) see *Appendix 2 & 4*.

In terms of National Response to the epidemic, four consecutive short and medium-term HIV/AIDS plans were developed and implemented from 1987 to 2000. The National AIDS Council, established under the office of the President, is responsible for implementing and coordinating the multi-sectoral response (WHO 2005).

The National Strategic Framework for HIV/AIDS for 2001-2005 outline a multi-sectoral and decentralized health sector response to HIV/AIDS, covering prevention, surveillance, care and treatment. An Initiative to expand access to ART was launched in 2001 but ART was formally introduced in public health facilities in 2003. (UNAIDS/WHO 2006).

One of the strategies for implementing the 2006-2010 Strategic framework, is to strengthen access to medical treatment care and support services. The actors include all government ministries, non-governmental organizations (NGOs), community based organizations (CBOs), faith based organizations (FBOs), PLHIV Organizations (Burkina Faso, CSLS 2006-2010).

In the area of ART, all districts can implement. However, the limitation in number and skills of health workers, and the requirement for patients to contribute financially (10 euro per month per patient) on ART are challenging the treatment scaling up.

According to WHO, 48 000 people were in need of antiretroviral therapy in 2007 while, actual number of people receiving ART was estimated at 15 888 (43, 1%) at the end of 2007 ((UNAIDS/WHO, 2008); see *Appendix 3*).

1.1.3 Health Care System in Burkina Faso

The Health care system in Burkina Faso is divided along administrative borders into 13 regions and 60 health districts, with 4 levels of care as follows: health centre, district hospital, regional hospital and national hospital or university hospital (Bodart, 2001).

Alongside the public sector, and the private sector, the law acknowledges the traditional healers.

Since 1991, the country initiated important reforms in the health system, after adopting Bamako Initiative:

- National and regional hospital were progressively given autonomy in financial and personnel management
- Health districts were created under the management of district teams
- In 1993, health centres managed by committee, were allowed to retain funds collected from fees and the sale of drugs, (Burkina PRSP 2004).

Like other developing countries, Burkina Faso health care system faced a workforce shortage - one physician/35 450 - in 2004, (Burkina Faso MoH, 2006).

1.1.4 HIV/AIDS therapy at the CMA of Pissy in Ouagadougou

Pissy health district is one of the four health districts that constitute the Ouagadougou (capital city) health Region. The Pissy district has a population of 664 849 with 80.73% being urban. The overall HIV prevalence was estimated at 2.6% (Pissy District Plan, 2007).

The CMA of Pissy is the hospital of the health District of Pissy. It has all services available at a district level, along with surgery and laboratory services (including CD4 and biochemistry). There is a hospitalization service that admits patients and provides 24 hours cover.

All services are paid out of pocket except ART and HIV/AIDS related services, which are subsidized by MSF; and thus, 'free of charge'.

The Medical Centre is the only one public structure that dispensed free ART and related services. All form of patient financial contribution (except transport cost) has been removed, making ART truly free. Indeed, since 2002, the Pissy district in collaboration with MSF has opened within the Medical Centre an HIV/AIDS case management clinic. This clinic is integrated within the OPD (Out Patient Department) service.

The staff is composed of 6 doctors, among which, 3 are MSF staff, 1 clinical officer, 6 nurses, 1 social worker and 6 counsellors.

Since its inception, the program has registered 4 100 people living with HIV among which, 2947 patients started ART. The outcome of ART program is as follow (Zachariah, 2007):

- Alive and on ART: 2374 (81%)
- Died : 324 (11%)
- Lost to follow up: 153 (5%)
- Transferred out : 67 (2%)
- Stopped treatment: 29 (1%)

1.2 Literature Review on adherence

1.2.1 Definition of adherence

According to Chambers dictionary & thesaurus 2007, 'adhere to something' is to stick or remain fixed to something; it is also to follow a plan, a rule... exactly.

For WHO, adherence is the extent to which a person's behavior (taking medication, following a diet, and/or executing lifestyle changes) corresponds with agreed recommendations from a health care provider (WHO, 2003).

In the area of health care, the terms "compliance" and "adherence" are used to define the patient's behavior in relation to prescription. Up to now, the term adherence still not well known by many care providers compared to the word compliance, which was widely used. Although, the progenitors (Haynes and Sackett) of the term compliance, claimed "compliance" was interchangeable

with “adherence”, (Lutfet, 1999), some authors clearly distinguish the two concepts. Indeed, for Lutfet, the term compliance suggests that patients acquiesce to, yield to, or obey physicians` instructions. It implies conformity to medical or medically defined goals only. The term adherence on the other hand, captures the increasing complexity of medical care by characterizing patient as independent, intelligent and autonomous people who take more active and voluntary roles in defining and pursuing goals for their medical treatment.

In other studies the term ‘treatment adherence’ refers to the ability of the patient to develop and follow a plan of behavioral and attitudinal change that ultimately serves to empower him/her to improve health and self-manage a given illness. Specifically in HIV/AIDS care this term refers to the ability of a person living with HIV/AIDS to be involved in choosing, starting, managing and maintaining a given therapeutic combination medication regimen to control viral replication and improve immune function (WHO, 2001; Asim, 2004).

1.2.2 Adherence behaviors patterns

Treatment adherence varies from patient to patient. Thus, the inadequate adherence has been described in the literature. Indeed, Zelee et al. in 2003 identified some behavioral patterns that undermine optimal adherence. These patterns include:

- Taking of medication very rarely (once a week/month)
- Alternating between long periods of taking and not taking medication
- Skipping entire days of medication
- Skipping doses of the medication
- Skipping one type of medication
- Taking the medication several hours late
- Not sticking to the eating or drinking requirements of the medication
- Adhering to a purposely modified regimen
- Adhering to an unknowingly incorrect regimen

According to Donovan and Bake cited by Aspelung, (2006), three categories of reasons of inadequate adherence were identified:

- **Erratic non-adherence** due to forgetfulness, being too busy, running out of medication
- **Intentional non-adherence** where the patient deliberately decides not to take medication due to fear of side-effects or interference with lifestyle
- **Unwitting non-adherence** where patients do not adhere to treatment due to language barriers and low-level health care literacy.

1.2.3 Measuring adherence

Quantifying the level and type of adherence to Highly Active Antiretroviral Therapy (HAART) has been focused by many studies, resulting in the identification of multiple direct and indirect measures (Giordano, 2004; Walsh, 2002). The table 1 summarizes the type of method of measurement, its

advantages and disadvantages. No method is considered the gold standard (Osterberg, 2005).

Table 1. Methods of Measuring Adherence.		
Test	Advantages	Disadvantages
Direct methods		
Directly observed therapy	Most accurate	Patients can hide pills in the mouth and then discard them; impractical for routine use
Measurement of the level of medicine or metabolite in blood	Objective	Variations in metabolism and "white-coat adherence" can give a false impression of adherence; expensive
Measurement of the biologic marker in blood	Objective; in clinical trials, can also be used to measure placebo	Requires expensive quantitative assays and collection of bodily fluids
Indirect methods		
Patient questionnaires, patient self-reports	Simple; inexpensive; the most useful method in the clinical setting	Susceptible to error with increases in time between visits; results are easily distorted by the patient
Pill counts	Objective, quantifiable, and easy to perform	Data easily altered by the patient (e.g., pill dumping)
Rates of prescription refills	Objective; easy to obtain data	A prescription refill is not equivalent to ingestion of medication; requires a closed pharmacy system
Assessment of the patient's clinical response	Simple; generally easy to perform	Factors other than medication adherence can affect clinical response
Electronic medication monitors	Precise; results are easily quantified; tracks patterns of taking medication	Expensive; requires return visits and downloading data from medication vials
Measurement of physiologic markers (e.g., heart rate in patients taking beta-blockers)	Often easy to perform	Marker may be absent for other reasons (e.g., increased metabolism, poor absorption, lack of response)
Patient diaries	Help to correct for poor recall	Easily altered by the patient
When the patient is a child, questionnaire for caregiver or teacher	Simple; objective	Susceptible to distortion

Source, L.Osterberg, T.Blaschke, *NEJM*: 2005

Hardon (2006) reports that, two measures are frequently used when reporting adherence to ART. The first is the overall adherence recorded as the number of tablets taken correctly as a proportion of those, which were prescribed. This measure is an important marker for the clinical evaluation of patient and counselling purposes. The second measure report the percentage of patients taking at least 95% of their tablets correctly, and it is essential for public health programme evaluation.

Indeed, some studies (Nischal, 2005; Kgatlwane, 2005) show that with 95% adherence, viral suppression is below detectable levels. However, a fall in adherence to 70% drastically decreases viral suppression to 33%. Then, optimal adherence has been defined as adherence of 95% or more and suboptimal adherence as less than 95 %.

So far, most of adherence studies conducted in West Africa particularly in Burkina Faso have used pill counts, pharmacy refill data and patient self-report methods (Niamba, 2006; Oumar, 2007; Eholie, 2007; Diabate, 2007; Etard,

2007). In Burkina Faso In 2006, Niamba study at Hospital and CBO facilities setting, showed an adherence rate of 58,5%.

Lack of standard methods to measure adherence makes comparison of research findings very difficult. Every tool either over or under estimates adherence. In order to reduce this discrepancy, the use of combination is preferred and advisable (Miller, 2000).

1.2.4 Adherence support system at the Medical Centre of Pissy

HAART adherence counselling (patient education) is an integral part of ART protocol at the Centre Medical of Pissy. Adherence programme consists of four preparatory sessions, which includes a mix of group sessions conducted by peer counsellors (HIV patients hired by MSF) and individual sessions conducted by professional counsellors (social workers, nurses, doctors).

Adherence counseling includes basic information on HIV/AIDS and its manifestations, benefits and side effects of ARV medications, how medications should be taken and the importance of not missing any dose, but also eating patterns, which accompany medication (alcohol, coffee, tea; cigarette, cola nuts...).

It includes also an assessment of patients' understanding of the therapy and their readiness for treatment.

After treatment initiation, sessions consist of side effects reporting, pill counts and an ongoing preventive counselling each time the patient returns for drugs supply.

2.0 Problem Statement/Objectives/Methodology

2.1 Problem Statement

In June 2001, U.N. General Assembly Special Session (UNGASS) on HIV/AIDS for the first time reached global agreement that the pandemic was not only a public health crisis but also a threat to societies and international security. The Declaration affirmed that access to medication in the context of pandemics such as HIV/AIDS was fundamental to the realization of the right to health.

Following UNGASS, in 2003 WHO/UNAIDS launched the '3 by 5' strategy (3 million people on ART by the end of year 2005) in line with the universal access to HIV treatment.

Thereafter, the introduction of generic drugs and a boost in funding for HIV/AIDS programmes have enabled more patients in African countries to access ART.

Burkina Faso in collaboration with its partners, worked to scale up this access to ART.

Many authors have recognized the benefits of ART. Indeed, UNAIDS cited by Hardon, 2006 state that the introduction of ARVs in the 1990s brought new hope to people living with HIV. The increased availability of treatment has dramatically improved survival rates and lowered the incidence of opportunistic infections in people with AIDS.

However, despite these benefits, there are some problems. The biggest obstacle to successful treatment is adherence to medication.

Non-adherence to antiretroviral treatment has several implications both on the individual level and on public health as a whole (Metzler, 2007). Some implications include:

- the progression of the infection to illness and to death with its consequence on the family, the community and the country
- an increased risk of HIV transmission: the researchers found that the risk of transmission increase by 81% with every log increment increase in Viral Load (Tovanabutra, 2002)
- the development and spread of HIV resistant strains, the future problem of changing treatment regimen and the issue of affordability.

Antiretroviral therapy is a lifelong matter. The issues in relation to long-term adherence to treatment (at least 3 years treatment for our study) and how best to support adherence over time, are not yet discussed in Burkina Faso. Some factors influencing adherence among experienced patients, such as dealing efficiently with stigma and discrimination, partner and family support, ensuring access to ART need to be discussed.

The CMA of Pissy, which is one of the oldest and the biggest (3000 patients on ART) centers of ART in Burkina, may exploit experience of successful

adherence people to improve projected adherence strategies such as “patient’s autonomy”, and decentralization of the treatment.

2.2. Objectives of the Thesis

2.2.1 General objective:

To understand factors that contribute to adherence to HAART and the evolving challenges of people receiving free antiretroviral therapy at the CMA of Pissy, Ouagadougou, Burkina Faso in order to generate appropriate recommendations on interventions strategies.

2.2.2 Specifics objectives:

- To identify factors that facilitate long term adherence
- To identify factors that inhibit long term adherence
- To explore gender related challenges to adherence
- To provide recommendations to enhance adherence interventions strategies

2.3 Study questions

- What factors inhibit quality of execution of ART?
- What factors facilitate quality of execution of ART?
- What are the barriers of persistence of ART?
- What are the facilitators of persistence of ART?

2.4 Methodology

2.4.1 Study design

This study was part of a larger research carried out by the University of Amsterdam, University of Ouagadougou and the Royal Tropical Institute in the two main cities of Burkina Faso (Ouagadougou and Bobo-Dioulasso) and which involved the five major ART clinics among which the CMA of Pissy.

A qualitative exploratory research approach was used. A qualitative research was indicated to explore social phenomena and behavior using contextual data that emphasize subjective experience of patient.

The research team was composed of Georges TIENDREBEOGO, principal investigator who planned and conducted the research, two research assistants, six interviewers (two for the CMA of Pissy) and two typists.

I have been involved in this study during the following activities:

- Guideline details designing
- Pre-testing and finalization of data collection tools,
- Information of local health authorities in order to obtain the last go-ahead,

- Research mid-term and final reviews.

I have done the data analysis on the occasion of this thesis.

2.4.2 Study population and sample

The study population comprised of patients whom, at the end of December 2006, had at least, three (3) years antiretroviral therapy and were still under follow-up, at the CMA of Pissy. Then, the sample was purposely selected based on gender and length of ART.

Therefore, from the database of male and female adults, 16 people were selected with equal representation of men and women. The selection has taken into account the fact that having an appointment in the study period or being easy to reach by telephone. For more intense discussion, an infected nurse and an ART activist were included.

2.4.3 Data collection technique

We conducted an individual semi-structured interview. An in-depth interview provides a flexible tool to collect narrative data describing interviewee's perspectives.

Tape recorder has been used and the transcript of the interview was done in French.

2.4.4 Data collection procedure

This study was included in the research carried out by health district of Pissy, University of Ouagadougou, University of Amsterdam and the Royal Tropical Institute (KIT).

The study started after obtaining permission from Burkina Faso's National AIDS Council and the National Ethical Committee for Health Research.

The interviewers were trained in preliminary tests of the instrument (*see Appendix 6*).

Participants agreed on confidentiality and ethical issues and signed a consent form (*see Appendix 7*).

A series of three interviews per participant with one-month interval of time were conducted. The second and third interview aimed to verify the constancy of participant statement.

The languages used during the interview were Moore (local language) and French. The interview was conducted in a place according to the will of the participant and lasted about one to two hours. Participant was asked to describe major events of his/her life, strategies used to adhere, barriers faced in adhering, how treatment fits with his/her daily life and self-reported adherence.

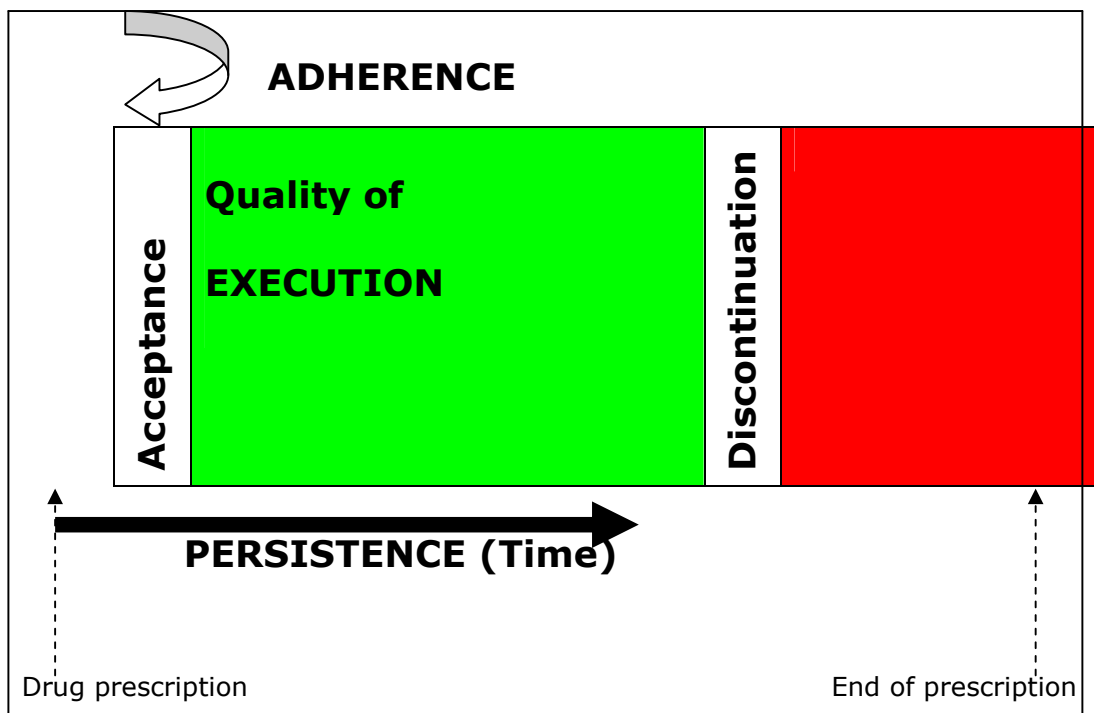
2.4.5 Analysis

2.4.5.1 Conceptual framework of patient's adherence

The treatment of HIV/AIDS with Antiretroviral drugs is most of the time ambulatory. Patients are living in their community and they have some contacts with health facilities or support services. Thus, we have adopted the following framework to analyze the determinants of adherence according to patient's perspective.

The figure 1 shows the different parts of an ambulatory pharmacotherapy.

Figure 1: Three phases of ambulatory pharmacotherapy.



Source Urquhart EJHP-S 2005

For Urquhart et al, (2005) a course of ambulatory pharmacotherapy has three parts: **acceptance** (of the treatment plan), **execution** (of the drug regimen), and eventually **discontinuation** (of dosing). For them, the first and third are essentially dichotomous, but execution is a continuous process. The time between when the first and last doses are taken is called **persistence**, expressed in units of time.

According to the literature and to our key informants acceptance is not only about the treatment but also about the disease. We found that acceptance of the disease and its treatment is not a one-time event but rather an iterative process. As such the Urquhart and Vrijens' linear model needed some adaptation in its use and analysis (see appendix 5 for original). We therefore, adopted a timeline approach, which enables to capture the different sequences and event.

The problem of chronic disease patients such PLHIV is how to ensure quality of execution and how to remain persistent of their therapy.

2.4.5.2 Process

For analysis, we used Microsoft Excel 2003 spreadsheets. To answer the study questions and achieve our objectives, factors were first classified in adherence inhibitors and facilitators. Then, factors of each class were grouped, into quality of execution of ART, and into persistence of ART.

In order to ease interventions strategies, factors were categorized as follows:

- Socio cultural and beliefs factors
- Economic factors
- Health care system related factors
- Therapy related factors
- Patient related factors
- Gender related factors

2.5. Limitations of the study

This study was limited to only participants receiving free ART. It would also be interesting to obtain data from patients who had to contribute (financial) to their treatment.

The sample included only successful and persistent patients. Data from discontinued patients might increase the validity of information.

The study was based on the patient's perspectives. Then, the lack of crosschecking participants self report through patient's record, within the health care services (triangulation approach), did not enable a thorough description of the quality of execution as shown the adherence model (figure 1)

People, who have discontinued or died were excluded, which means a lack of information on factors that lead to discontinuation.

3.0 Study findings

From January to March 2007, we conducted a series of three semi-structured interview with 16 participants in order to explore adherence facilitating and inhibiting related factors at the CMA of Pissy.

As shown in the previous chapter, the data collected were analyzed according to the model of ambulatory pharmacotherapy. We did not only consider the factors directly related with adherence such as taking drugs, regularity of medical appointment, but also other behaviors that can influence were part of adherence.

Thus, in this chapter, findings will be presented as follows:

- Factors affecting the quality of execution
- Favorable factors to quality of execution
- Barriers to persistence of ART
- Factors that facilitate persistence to ART

3.1 Quality of execution of ART

Quality of execution of ART in our study has been defined as the way, patients daily perform the agreed recommendations of its therapy. It include daily drug-dosing intake, dietary requirement, medical appointment, blood test, and the overall behavior required to avoid the infection of new strains or other type of HIV virus..

3.1.1 Factors affecting the quality of execution

3.1.1.1 Socio-cultural and beliefs factors

❖ Illiteracy

Illiteracy was related to reason to missing medical appointment or not taking medication on time.

"My appointment was on the fourth of this month. As I am not able to read, I showed my paper to a woman who told me that my appointment still ahead on time. She misled me". (29 years old widow)

"One of the difficulties we met is illiteracy. We are in Burkina Faso and most of the patients are illiterates. You ask somebody to choose his ARVs taking-time...problem, you tell him to take at 7:00 and 19:00 o'clock...problem. They do not know reading a watch, they do not know what 7:00 o'clock means,"(Key informant).

❖ **Lack of mentality of punctuality**

Lack of mentality of punctuality was frequently mentioned as a barrier to adherence. Several interviewees recognized that very often they take their drug with a delay from 10 minutes to two hours. A 38-year-old man said:

"Punctuality is a problem because we do not have this mentality of o'clock sharp, whereas our doctors advise us to be sharp on time. It is hard..., delays of 30 minutes, 1 hour..., that happens. I think I am not the one in this case. Those who are sharp in this bulk are very few"

❖ **social events**

Some critical events appear as an obstacle for medication. Three participants reported missed their dose due to these events.

"It was when my brother in-law dies. We were at the hospital in the night, and we went back. At 5:00 am, we received a call announcing his death. Then, I left in haste without any drug,"(39 years old widow).

"Treatment is taking drug in the morning, in the evening and when you want to go to bed. I have never forgotten even if sometime I have to drink alcohol during public holidays or during parties with friends...But sometime you are far from medication. I will not lie, if you offer me soft drink, it looks like you do not offer me anything. I have to take alcohol to be sure that I took something, even though I should wait 3 hours before taking my pills",(28 years old man).

❖ **Religion and beliefs**

Religion plays a role in the lives of people. It influences the way a person think and conduct herself or himself. Then, the quality of execution of ART may suffer from some practices. In this study, one participant comments on fasting and taking of medication:

"When I began with ARVs the first year, I was scaring, I did not fast. I ask myself, what all these things mean. Is it about dying...? Nevertheless, after death there is life, and this life needs to be prepared as well as the one in this world. Why do you want to catch few days in this world and spoil the life I have in the heaven eternally? I am convinced that one month gap cannot kill me".

3.1.1.2 Economic related factors

Even if ART is provided completely free of charge in this Medical Centre, other costs are challenging patients daily treatment. The problem of transportation cost, and food requirement were reported.

➤ **Transport difficulty**

Without the necessary money to travel to the care facility, patients will not be able to adhere to their therapy.

*"My mum used to make ram*¹, but currently she is tired... eighty years old! She is tired. Last time, she found transport cost for me. Rather I to offer her money, it is the opposite", (45 years old divorced woman).*

"Most of the time the patients whose ARVs run out, are those who live at 100, 200, 300 km from the Medical Centre. They do not have means to come for their drug supply. It is not easy", (Key informant).

➤ **Hunger**

Malnutrition plays a significant role in the morbidity and mortality resulting from HIV infection. In addition, the interaction of ARVs with the body system of those on ART can produce side effects that will negatively affect drug adherence and efficacy if they are not eating well. The ability of households to ensure their food security in the face of AIDS is being severely challenged. Nearly all participants mentioned the issue of hunger.

"ARVs are medicines that « dig the stomach ». To take them without eating does not give you more envy to take"

"I am not fine. Since this morning, I did not eat...anything, except the medication I took and my intestines are «talking»".

"I have never gotten side effect. Only the medication makes me eating too much. After taking drug if I do not eat, all my body is shaking with hunger".

"Food makes human being. There is no means... there is no means. Here you can do three months without any meat in your meal. It is difficult, there is no means".

"That gave me a lot hunger and I got up the night to eat. If I do not find to eat, all the eyes redden and there is no longer sleep".

3.1.1.3 Therapy related factors

One participant has reported an interruption of his treatment due to side effects.

"I do not neglect my medication. I took them well. But, since I start with this new drug and I lose blood, I no longer know".

3.1.1.4 Patient-related factors

Some patient based factors seem to have strong relationship to treatment adherence. The most frequently noted by the participants are fear of disclosure, forgetfulness, being away from home, feeling healthy.

¹ Local alcohol prepared and sold by women

Fear of disclosure

Disclosure according to WHO, (2005) means revealing or uncovering information about a person's HIV status. Disclosure appears as a subject around which, all the coping strategies are targeting. Very often, they want to avoid taking medication in public places. Some of reasons are as follows:

"It is necessary to always be discreet in taking drug...in all those things. Otherwise, disclose it to other and they « kill » you before your disease".

"If people see you taking your pill, they will ask you questions, thereafter, they will « sell your name » everywhere... all those people who did not know your sero-status will know of you... and no one will want to be close to you or to greet you. That is why I hide myself to take my medicines".

"To be infected by HIV is a subject very taboo. As soon as you say that you are a person that lives with the virus, one does not see you living with a virus...one sees you as dead"

"Sometimes, I wonder...should I tell my formers sex partners to do their HIV test? Ah! If their results are positives, I will no longer able to keep my secrecy".

Forgetfulness

Many participants have reported forgetfulness as one of the reasons for non-adherence to ART.

"The fact to think, how to nourish my children, is sufficient to forget the taken one your tablets".

"Sometimes at the level of the work, you are under pressure. Frankly, I do not know...sometimes you know that it is the taking hour and something intervenes as that, you forget for one, two hours. After you remember now, that I should have taken".

A participant thinks that the causes of its forgetfulness are rooted either in the disease or in medicines side effects.

"I was nonetheless a very meticulous person; very...I could not forget something easily. But nowadays, I really can forget a lot of things and this is three days, a week later, I will remember it"

Being away from home

Truck drivers, traders are more concerned by this issue.

"Some truck drivers tell themselves to be able to return on time; as soon as the stay is extended they are obliged to be in rupture of medication. They are followed by their employers... if the truck drivers told them that they are under treatment, employers can dismiss them", (Key informant).

✚ Feeling healthy

One participant talking about taking medicines on time, said:

"...Yes ...Can be once a week or a month...it may happen...because, in the end, when one recovers, one no longer sees so, the importance of the thing".

3.1.2 Favorable factors to quality of execution

This subchapter includes facilitators related to the community, to the providers, and especially to the patients themselves.

3.1.2.1 Community/family support

"I take my ARVs twice a day, 7:00 and 19:00... I do not know hour but the children know it. Through the radio, they tell me that it is time. Now, I have a girl that got a mobile phone, and when she is at home, she indicates me the time so, I can take my medicines on time... but they do not have any information about my disease."

In contrast to most of the participants some find out many advantages in disclosing their infection to family members

"My spouse reminds me every time. For example at 20:30 pm if I am at home, she reminds me. Even the weekends, the mornings, if I forget, she reminds me. My children also, from time to time say: «dad, it is time to take your pill». They know that I have the virus and I have to swallow my medicine at 8:30 am and 20h30 pm".

"If I am at home, I tell my daughter to look at in my bag and bring a medicine and a glass of water. When I say, «looks in my bag and bring a medicine and a glass of water», she knows what does it means. She says, «This is hour for Mom»".

One participant talking about his wife, who did not adhere to prescribed regimen, state.

"I even inform his father. The day before yesterday his father invited her at his home to discuss about the medicines taking and its importance. That to urge her to better following treatment. If I had hidden our sero-status, I would have not been able to refer to my father in-law".

3.1.2.2 Facilitators related to Providers

Two participants have recognized that, execution of their ART is link to health care providers. It is come out that, patient's readiness to start ART is an important facilitator

"I trust in doctors. You must follow what doctors tell you, and if, it does not goes well while taking the medication, you have to see them again. It is necessary to follow the indications of the doctor. It is not necessary to say that I am not fine, so I will stop taking now... speak to your doctor".

"This strong need to stick to my treatment is due to the psychological preparation before the treatment debut".

3.1.2.3 Patient-related facilitators

This section regroupes all reasons, behavior, strategies developed at individual level, to ensure daily drug taking.

❖ Acceptance of the disease and its treatment

"That can happen to anybody. If you are infected, it is necessary to accept, it is necessary first to accept the disease, if you do not accept, it is difficult... that even cannot go, if you accept, that can go".

"It is necessary first to accept that one is sick and that one can overcome this disease".

"If you really accept, I have this illness but I want to go into battle, you will be able to arrive. Otherwise, if you say that the test...may be doctors are mistaken... Is it really this disease? ...I think that blood test was not well done it is not this illness. Even if the person starts the treatment, there will have a period she will delay or stop the taking of drug just to verify, if, it is really the disease".

❖ Seeing positive result

"To swallow... swallow as a hen is not easy. However, presently, this is a choice, swallow the pill everyday and I have my health. I prefer it, that abandon and see resistances, and that can cost me life".

"You take the medicines because of your own health, because you want to be healed. I think I still alive and able to exchange with you today because, I always take the medicines".

"ARVs are something well, because, even if you are weak, even if you are slimmed and you take it constantly, no one will know that you have this disease".

"To put me under ARV allowed me to solidify my morale. Because I tell myself, I do not leave adrift nonetheless... there is something that allows me to stabilize my disease and to be able to hold again some days. This already is a good thing".

❖ **Taking medication secretly**

Most participants indicated that this is the way to avoid risk of disclosure.

"If people see you, everyday swallow the medicines that can push them to ask you many questions... to seek for understanding. I know how to take my medicines... for that, no one sees".

"...I am afraid of malicious gossip. Very often, one insults in front of me the persons that are infected... «This person has AIDS, he will die, wait and see»... and me, I listen... you know that the disease name is not well to hear. I hide myself to take my medicines".

❖ **Incorporate treatment in daily routine**

"...I have a reserve's plastic bag where I put aside everyday my reserve's pill in the evening... for mornings and for evenings, I swallow the two ones at 7:00 and the other 2, I put them in the plastic bag then, in my pocket. It is like that, everyday".

"...Because this became as a food for me. I cannot forget to eat in the morning. For example when I get up in the morning, ..., when I finish to brush one's teeth, I wash.... when I finish to eat only, with....the water that I will drink , I accompany the medicine at the same time. Then, evenings also, as soon as I will return...."

"This is the thing that one must keep it in mind when one doing something. This became now «our umbilical cord»... One is hung to that. One inserts that in the program. I have such activity to do ... at that hour, I have first to stop ... do it, and then continue".

❖ **Feeling like something is missing**

Some participants point out that around the medicines taking time they feel something strange working like a trigger.

"If you did not take it on time, you feel... in fact, it looks like you are looking for something that you forgot. You no longer are yourself".

"...then once it is time to take and you do not..., when it is time and then you do not take, you feel something in your organism that reacts strangely, you know, that you must take".

❖ **Coping strategies**

These coping strategies are used either to ensure the daily taking of medication or to avoid disclosure at a place considered as non-favorable. Among strategies, "assimilation" of HIV/AIDS to another common disease is widely utilized.

Some participants prefer to **take their pill in advance** to avoid forgetting.

"...But, often when I feel that I am doing something and it remains me maybe twenty (20) minutes, and I know that if I do not take it in the twenty (20) minutes I will forget, I prefer to take before the twenty (20) minutes"

Nearly all participants said they **carried their medicines** for any trip.

"...I circulate everywhere with that, I travel with; It follows me everywhere, when it is time I take my medicines... I can put myself in a corner to take my medicines".

"When I know that I leave for somewhere and I am not sure to return on time or I am not sure to return the same day, I take a necessary dose that I send with me. In addition, even when I travel, if I know that I must travel for a work, and this work must take maybe one day, I foresee three days medicine...In case of extended work or breakdowns along the way... therefore I always foresee these things".

Those who avoided disclosure **assimilate HIV/AIDS to another « acceptable disease »**

"My illness ... when I arrived in the neighborhood, for many people, It is foot illness... foot illness. Me, I told them, the doctors said: « takes this medicine and your illness will leave ». So, in front of people, I take that, I have no fear, I have no shame". (46 years old woman with physical impairment)

"...This is a disease like others; often one asks me, but I say that, this is malaria. A malaria problem, that's all".

"One day, a foreigner came to our house. She saw the pill in my bag, and says that she has headaches; I right away withdrew my bag telling her that, this is not «Paracetamol». This medicine is for heart illness...Do you have a heart ache? ...She said no. I told her that this medicine is for heart".*

Except four participants, all the other participants hid to take their medicines

"I put the pill in a sweet packet. When I arrive, I open, I throw the packet of the sweet, I put it in my mouth, with water, and I swallow my medicines"

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"If I am at weeding or naming ceremony if it is time to take, I hide myself to remove my medicines, I put in my mouth then I pierce a packet of water and swallow my medicines. People think that you drink water, while you take your medicines".

"...if it is outside that I am, I pretend to look for papers in my bag I remove my medicines and I look for water somewhere... I swallow and I return to sit as it was nothing; that is not difficult for me"

"Sometimes I am obliged to go to the toilet when I am in a family; I take my bag, I ask the kettle and with this kettle water, I will take that".

The participants used many **reminder tools**, which included Watch, Alarm, Mobile phone, Radio, Siren, Notebook, and Muslim's muezzin call.

3.2 Persistence of ART

Persistence of ART in this study is when one continues the treatment in spite of difficulties encountered.

The effectiveness of ART is due to the quality of execution but also to treatment persistence. Currently, maintenance of treatment is only the way to control patient's virus load. However, many obstacles hinder persistence of ART.

3.2.1 Barriers to persistence of ART

3.2.1.1 Socio-cultural and beliefs barriers

➤ **Religion and belief**

Some beliefs or faith can lead to treatment interruption.

"The power of God really is great, because God calms us, if you trust in God, you can be healed even if you do not take any medicine".

"I have seen with one that I knew. She began to take the medicines. She was fine and she stopped...she tried to use local medicines. She died, she left as that".

"...Our Minister said, «Those who trust in God and knows that God can do something in their life... it happen». Personally, I knew a woman that came from Botswana, tell us that she was judge when she knew she was infected. Then she said: « Lord, I will not go to hospitals, to be going to die, I want to remain in front of you, I want to pray and I would like to beg you, to do something for me». Thank God, she healed and she came to testify".*

"The prayer helps... here a person that gave a testimony, she also had the disease but, by the prayer power she did her blood test in three different laboratories, and all became negative. And one returned thanks to God".

➤ **Stigma and discrimination**

Stigma and discrimination remain a big issue in this area; that may strain persistence to antiretroviral therapy. All participants were feeling or being stigmatized, or completely discriminated.

"...Otherwise, at my office, I know there are people for example, who do not utilize the same toilets that me; I have identified people that never entered in the same toilets that me... There are some people, who even buy the bleach... I know that, this is because of me".

"...For certain people, this is a shame... this is shame, one woman refused to take the medicine, but she died... coming in the hospital, at AIDS section and being look at by people, they see that as a shame, they are ashamed".

"Often, when you are somewhere, you have got a feeling that everyone eyes are pointed on you. This is that especially".

"...Hum! What my sisters said to me..., «You are condemned, therefore in this case, it would be necessary to prepare yourself and when one says that to you, this is for you; because you will be able to prepare the future of your children. The day you will leave that will not surprise you»."

"We ate all together in a same dish. They put my food separately. When I eat, and if there is a rest, when I invite the children to eat it, their mothers call them back and told them to do not come close to me. They even said to my girl to do no longer wash my clothes and asked her if she knew which disease I suffered." (40-years-old widow, living in father house with brothers.)

"One of the little brothers of my deceased husband said to me that, what we ate together, we will« defecate» it together. That means that, I and my husband have been infected together and both of us will die".

One participant indicated that some patients do not want to utilize the nearest health care facility from their house, because of stigma.

"Some say that they is not suitable to be going to treat in your neighborhood that you meet people you know... But me, I am here and I come to take my medicines here. The one that saw me...the one that did not see me also, this is that. I will not go elsewhere to take my medicines. I remain here".

3.2.1.2 Health care services barriers

A poorly organized health care service can discourage patients in their efforts towards adherence. Some participants' viewpoint is as follows:

"The reception is not good. Also for the medicines supply, you have to queue; this is not easy".

"I see sometimes, one shouts at patients... if you are sick, you arrive to the health center, one shout, speaks to you poorly, that can worsen the disease".

"The system of ARV supply is not decentralized; therefore if you are in province it is difficult ... to find time each month for supply. While one has not a financial means for that, and this is even tiring for patients".

One participant stated that the poor information given by providers is also an obstacle for long-term adherence

"... In reality, they are not convincing in what they call resistance. Because a patient is stubborn, this explain why, we patients sometimes we do not take or shift the taking time. At the beginning, one told us, it was necessary to be strict, to still alive, to recover. We understood that... effectively, we have recovered and we are back in the society. However, one tells us, you will do resistance if you do not adhere... what is resistance? For me, this is just to persuade us to be persistent".

3.2.1.3 Economic related barriers

With the time, patients have more concerns on **how to find job or how to match their job constraints** with health care organization program.

"I need a job...a work that I can do, to be paid at the end of the month, and to be able to buy the condiments".

"You lose practically two days. This is for every month... you have to go to the health facility for medical visit, for drug supply, for blood test. This is not easy for somebody that works especially in an administration like ours".

"Today you ask someone something, tomorrow you ask him again, the day after tomorrow... that lead to stigma and discrimination. Finally, no one wants even to see you again. Now, how to ensure everyone with little means for basics expenditure...that is the problem! Moreover, with the disease, many can no longer do what they did before".

3.2.1.4 Patients related barriers

- **Fed up with medicines**

"I know a lady who let herself die from that, since she said that she will not be able to take pills his entire life".

For this participant taking drug endlessly is a chore

"This is annoying, maybe a certain age, I sit one day, I look, I have two children, these children are rather big, and they know how to manage on their own... I say fuck! ... Stop this chore".

One participant tells, how she lost her friend, who wanted to be free from ARVs

"She said to me, «It is a lot, you do not see, it is a lot I cannot take all this pills. It is this medicine which will kill me», I say no, it is important to take, if the Doctor has prescribed it for you, he knows that it will help you. Unfortunately, she said no... her health gets worse and they took her to the village...and she dies there".

- **Feel healthy**

Nearly no participants respect the diet that should accompany the ART. Whether they do not drink alcohol but they drink tea or coffee, or smoking...

"After two years, my health evolved a lot. Then, I have started to resume the life as I lived. Then, to drink beer, go out, to eat what was forbidden".

"When doctors say that do not drink alcohol, do not take exciting products such as coffee, tea... even Coke! All these things, it was at the beginning ...There is nothing".

3.2.1.5 Gender related barriers

Through participant's statements, it is evident that some gender-related factors may influence indirectly adherence of ART

- **Homelessness**

Two interviewees point out that most of the homeless patients were women. Homelessness is a manifestation of social discrimination due to AIDS, which affects especially women at this area.

"I have no relative, in case of emergency I will die for free; not very long time ago there is a young girl, we lived together under the shed... because since his family came to throw her out, nobody asked about her until she die".

"You have nothing to do, the family does not take care of you, it is difficult... ah... it is difficult, me, I see many women that come to stay at the Medical Centre".

"I even saw an old woman of 67 years that has been sacked by her husband, when she discloses her status to him".

You see this shed, people are sleeping there; presently we found a house where we have transferred some of them.

➤ **Low utilization of health facility**

Men are known for their poor health seeking behaviour. Some participants pointed out their experience.

"Women utilize the health facilities more than the men do, because many men prefer remained in anonymity. That is what we see."

"When the woman, while on treatment tells her partner to do the test, this one reply « what stories! Someone who is sick is physically like that? ». Then, it will be the latest stage of the disease he will come"

➤ **Poverty**

Poverty seems to affect women especially unemployed householders. Some participants mentioned here their concerns.

"Really, there are many women like me; because your pride is for example if your husband was still alive, then you can help each other. He does no longer exist. Therefore, you have to cope to feed your children... what about yourself?"

"One has health, one has the force, and one has no work. You can pass two months without having 500 CFA in your hand, and you say that you live; therefore it is difficult for us". (45-years old woman)*

➤ **Child desire**

Participants frequently bring up the issue of wishing to have a child. As soon as people feel healthy, motherhood becomes one of the key issues.

"The woman when she is anxious to have a child, the problem around, she does not care. Often, that creates conflict between her and me". (46-years-old man)

"I asked health workers and they said that if you are taking ARV and you desire to have a child, they can follow you until the delivery but, you will not breastfeeding the child. Since I am on ART, I was wondering... ah... if I could also take a pregnancy".

"...This is Madam who is rushing, because she sees other women do it. They take pregnancies and thereafter say to health workers that it came accidentally".

One participant tells, how she interrupted treatment for motherhood reasons

"The day of my delivery coincided with the day of my appointment. Therefore, I missed this appointment for a long time... Ah! However, when I came, they understood. They consulted me, they gave me medicines, and I returned with my child".

3.2.2 Factors that facilitate persistence to ART

3.2.2.1 Social cultural and beliefs facilitators

Religion

Religion seems to be a strong support for our participants. Whatever the religion practiced, all participants are unanimous that it is helpful on acceptance of the disease.

"...Because of the disease, we have always gone to pray, that encourages those who were afraid, and people are more and more numerous".

"When one puts the belief ahead, all becomes easier to accept. Any problem let it to God, really that becomes easy".

"It is written somewhere, that suicide people are not admitted at heaven. If I refuse to apply what it is necessary to do to survive I committed suicide... in clear terms, I must take my medicines".

"At the prayer, the fact to meet again is already good you belong to a same family, we have esteem to each other, on one is detested, we are singing, we pray, we listen the word of God, and we separate in happiness".

"In our church they always said to us: «take your medicines regularly and pray, continue to pray, even if God leaves this illness... that he gives you health and that your soul be deliver»".

Self-support group

Self-support group comprise people living with HIV that are taking or not taking ART. Among participants, some were members and they expressed the positive effect of these groups in the persistence of treatment.

"If you see us in our association, you will not say that we are sick. Here, people are comfortable. If you stay every time at your place, it is loneliness, you think the medicine that I take...is it for how long? Nevertheless, when you

are in-group, you forget all these things, you forget, it is something else that preoccupies you”.

“Patients are gathering there to exchange. The chats console, give more courage... one shows us, how we must take the medicines, never forget, never abandon. If you listen and you follow the advices, it is good”.

“The fact to meet other persons in the group and know that you are not alone... of what will you be afraid? This is a consolation for the patients”.

“This is better to participate at support group’s discussion. If you go there, there are exchanges ... that can facilitate you in your life; what you had and you could not bear, with many people, you will realize that you can continue... that cannot do anything to you”.

3.2.2.2 Patient related facilitators to persistence to ART

❖ Acceptance of the disease and its treatment

Many participants have recognized that acceptance is the key point to overcome the multiple challenges they are faced, and to persist in their treatment.

“This disease had become in reality as my spouse, it replaces my spouse and I must fight to live with it. That is all ... when I have accepted it as my spouse; I no longer feel it like that. I should have trailed it. I mastered this disease”.
(39 years old widow)

“Never wonder where I got this disease; you must say, «But now, that I have this, what I have to do to prevent it to evolve? On the other hand, if, it is in evolution phase, what should I do to get it regressed? »”.
You should never lose the morale. We are here... we are taking our ARVs... okay.... How many people in good health are died while we still eating? We are going to their burial nevertheless they had nothing. That means, being infected by HIV is not synonymous with automatic death.

Sincerely speaking, I find that Aids is better, because with hypertension crisis, you can die on the spot, but Aids, there is no problem... if you follow the instructions of the doctor your life is well.

This is a chronic infection, it is necessary to take it like that. How many chronic infections there are? How many people take medicines every day? How many people inject medicines themselves? There is all kind of situation.

“We did not take our money to buy this disease; if the disease will catch you, it will catch you”.

❖ **Living for someone**

Some participants stated that they live for family especially those who lost their spouse

"The craving to live... to be useful to my family, it is that. Because me, if... if nowadays I was not here, I do not know what my family would have become. Therefore, this is really the family reasons. When one lives, one can do many things, but when you do no longer exist... it is terrible".

"If you do not follow the treatment and that you die, those who are behind you will be affected; for example the children that you pay the school, you take care and nourish. If in 2000, I was died this is a problem; because, besides my own children, I already have five orphans that I have to take care".

"You must follow the treatment to be able to get few days to take care of your children; until God..."

❖ **Seeing positive result with ART(healthy)**

"You have the medicines, you take it and this is well, you can work without problem this is well. You are not on bed as before, you no longer suffer from small diseases, and you are forceful to do any job... hein"

"I continue to take my medicines because it is first the morale and the fact that I am in good health".

"At the beginning, I was weak; but now, as every time, I see that there is improvement and that I live normally. This is giving me force continue. I believe that I should always continue".

Without ARVs, presently I would have been on bed or dead, but since I begun this medicine, I am in good health, I am satisfy, therefore me, I do no longer count myself among the patients; I will never stop.

"With this medicine one becomes «complete»; a complete person means that this person no longer suffers from small illness everyday, always saying, I am... I have that... This person lives normally, makes activities as everyone, can go everywhere, and does not feel indexed by the society".

❖ **Disclosure**

Even though, for most of the participants disclosure is not on their agenda, some of them have seen many advantages with regards to treatment persistence.

"When you take your courage and you say it to the people, I believe that one does not reject you. Indeed, we tend to conceal... to hide this illness; when people discover, they think that you are criminal or you want to transmit them the disease".

"I do not hide myself anywhere. As I said to you that at the office, a marriage place, whatever the place where I am, I take my medicines... me, I do not hide myself".

"The disclosure is better, because if you disclose you will find benefactors that will help you; but if you do not disclose, this is you and only you; and you will suffer".

"... There are people until now, when I say that I have Aids, some say that here an unreliable guy, he only has strong character; he lies to get money of Aids. Then, that make me laugh. While at the beginning, certain already suspected and murmured, «He has Aids» Nowadays, when myself, I say that I have Aids, one does not believe me anymore".

4.0 Discussion

Participants in this study as described in the previous chapter, identified different factors that might influence adherence to ART. Some factors were interlinked depending on circumstances of time or events (fear of disclosure and stigma, homelessness and hunger,. Thus, the following factors were identified as facilitator or barrier: illiteracy, religion, hunger, transport, fear of disclosure, forgetfulness, feel healthy, acceptance, secrecy in medicine taking, stigma and discrimination, homelessness, community and family support, living for someone.

Then, in this chapter, we will discuss our findings, the specificity of the study setting in relation with the literature.

4.1 Illiteracy

According to our study, illiteracy is a barrier for quality of execution of ART. Indeed, illiterate patients have difficulties to check the dose-taking time, the date of medical appointment. This may lead to low HIV/AIDS literacy that can undermine efforts to make PLHIV autonomous.

Our finding corroborate Sipler, (1999) who found that management of HIV-infection with ART is complex, especially among illiterates. Goldman, (2002) also found a large differences in adherence to treatment regimens by education and that differences in complying with treatment significantly affected overall health status.

Dahab, 2008 in his study found that providers reported that lower level of education was strongly related to poor adherence but patients interviewed did not share this view. The author concludes by saying that it may be possible in multilingual setting (language barrier).

Although, patients use social support, reminder tools to overcome illiteracy effects on their treatment, illiteracy remains an important barrier that increase patient dependency to a person or to a place.

4.2 Hunger

Nearly all participants have mentioned the problem of ART and hunger. Many studies (Hardon, 2006; Gillespie, 2005; Metzler, 2007) showed that hunger remains a big issue for ARVs users in low-income countries.

Castleman in 2004 stated that interaction between ART and food and nutrition could affect medication efficacy and adherence to drug regimen. For him it is recommended that asymptomatic PLHIV increase energy intake by 10% over the requirement for healthy non-infected person of the same age, sex and physical activity level and symptomatic PLHIV increase energy intake by 20-

30% over the requirement for healthy non-infected person of the same age, sex and physical activity level.

In our study setting, many people already struggle to maintain a steady diet. Therefore, food insecurity is worsening with HIV/AIDS; most of the time the breadwinner is dies leaving an infected partner and vulnerable children. However, as Hardon said, people complain about hunger during the initial stages of treatment.

We did not get any evidence on stopping or skipping medication because of hunger, but according to the finding, food support should be brought at this critical period of accelerating recovery.

4.3 Religion/beliefs and acceptance

Religion seems to play an ambiguous role in our context.

On the one hand, religion appears as the latest « remedy » which can completely cure HIV infected people. As one participant said that if you trust in God, you can be healed even if you do not take medicine. Messages given by some religious leaders to their followers do not encourage the continuation of ART. Then, in this view, religion inhibit adherence. Indeed Wanyama, 2007 in Uganda found that 1.2% of patients discontinued ART because of a belief in spiritual healing.

On the other hand, religion is a source of hope, morale and acceptance of the disease. In our context, HIV has been considered as disease of sexual misbehavior, disease of shame, therefore, blamed by society.

Acceptance of the disease in this environment, require many efforts to HIV patient and religion very often, could be helpful. Religion can lessen psychological distress related to the condition of being HIV positive. The acceptance of the disease and its treatment improves the chance of adherence.

Indeed, Peter, (2004) mentioned that religion strengthen people's ability to cope with life threatening disease and its importance in predicting aspects of psychosocial need of patient.

As for Clark cited by Aspeling (2006) describe hope as inspiration and vitality. The loss of hope is equivalent to a lack of eagerness, desire, and certainty about the future and loss of meaning and purpose of life. For him faith helps people to make sense of the world, and acts as basis for daily decision.

Thus, regardless of the strategy used to enhance adherence, religious leaders should be involved.

4.4 Transport costs

We found that patients who live far from the Medical Centre met problems to adhere due to transport issue. Some patients live over 200km from the facility

and complying with drug supply, medical appointment, and blood test is a problem.

In Burkina Faso, antiretroviral therapy is not yet practically decentralized. Many reasons, to our point of view contribute to that. It includes shortage and lack of skilled health workers, poor coverage in ART support services such as laboratories for blood test, counselling, ARVs storage.

Hardon, 2006 showed that although patients received medicines free of charge, transport costs are an important reason why ARVs users fail to visit the health facility for follow-up and to get new supply of drugs.

Mills, 2006 stated that traveling long distances to receive treatment was common in developing countries, transportation difficulties were often reported to be a major hindrance to adherence.

In reality, at our study site patients made long distances because this facility is the only health structure where ARVs and other ART support services are truly free of charge. In the other health facility, whether public or private, patient financial contribution is required. Even though in the public sector, the most poor have access to free ARVs after welfare services inquiry, the procedure remains unclear with high risk of compromise to confidentiality.

Another explanation of travelling long distance for treatment in our context is stigma. Indeed, to avoid stigma and discrimination, patients prefer being followed-up in a health facility far from their own residence.

Nevertheless, a real decentralization of ART, cuts of users fees related to AIDS may reduce the extra costs of the treatment.

4.5 Fear of disclosure and secrecy in pill taking

For a better understanding of the concept of disclosure and for a comprehensible discussion, we will refer to WHO, (2005) definitions as follows:

- *Voluntary disclosure*: is when the client (PLHIV) willingly shares information about his/her HIV status with other people.
- *Involuntary disclosure* happens when someone reveals someone's HIV status without his/her approval and/or knowledge.
- *Indirect disclosure* happens when the PLHIV does not actually tell other, but indirectly reveals his/her HIV status through things that he/she does, for example taking pills openly.
- *Full disclosure* is when PLHIV publicly reveals his/her HIV status to a person or organization for example family member, spouse, friend, support group or to media.
- *Partial disclosure* means that PLHIV will only tell certain people about his/her HIV status, example spouse, relative, counsellor or a friend.

Many respondents are taking their medicines secretly to avoid risk of disclosure. As we saw in the previous section, secrecy in pill taking can

facilitate adherence in this area. That may help patient to ensure the daily drug regimen and to obtain a certain quality of execution of his/her ART.

However, in the long term this strategy may not be sustainable. The continuous fear of disclosure that always accompanies the pill taking could be a factor of non-optimal adherence.

Vervoort, (2007) in his systematic review showed that secrecy is difficult to maintain and can be a risk factor for involuntary disclosure; when it is not possible to take medicine out of sight of others, adherence is hindered and a dose is easily skipped.

Some participants (most of them were AIDS activist or responsible of PLHIV organization) of the present study, who disclosed their HIV status, found many advantages. They do no longer hide to take their medicines; they are less stigmatized in the area of disclosure. They get more and more social support. For them, if you do not disclose, and people suspect that you are HIV infected, people think that you want to transmit the disease to them and that is source of stigma and discrimination.

Our finding from the present study were also similar to the one found by Hardon, 2006 in Botswana. She said that without disclosure, it becomes difficult to use medication in the presence of other people and it is difficult to have the privacy that would keep people from noticing regular medicine use. In this case, disclosure is a major facilitator of persistence to antiretroviral therapy.

However, most of the participants perceived disclosure as a risk of stigma, discrimination, isolation, and that it can even shorten one's life. The common view of this category of respondents was dominated by the threat of social exclusion. For them, the fact that HIV/AIDS is incurable, the society sees you as a dead person. Then, you lose at the same time, esteem, and role that the society had increasingly given you.

Concerning what has been said, disclosure could be in favor or against adherence to ART. Nevertheless, we maintain that a complete non-disclosure of HIV status maybe a big secret, difficult to maintain by an individual over time. It is not necessary also to reveal your HIV status to everybody; you have to measure the advantages and disadvantages of any decision to disclose. Thus, at least a partial disclosure to a family member or a friend or colleague might enhance PLHIV living conditions and facilitate an optimal adherence.

4.6 Stigma and discrimination

Stigma and discrimination emerged as a limited factor of persistence to ART according to our participants. As afore mentioned, people who are unable to be open about their HIV status have particular difficulty in taking their drug because of the need for secrecy. One participant said that it is difficult for her to adhere when she went to her parents because if you swallow every day they

will ask you why you take medicines. This is consistent with the finding of Weiser, (2003) who found that 15% of participants indicated that stigma interfered with their adherence to ART.

Indeed, Hardon, 2006 also found that stigma was a key constraining factor in Uganda, Tanzania and Botswana and ARVs users find that it is hard to take their drugs when they are among people to whom they have not disclose their HIV status.

For some of them, stigma and discrimination goes beyond ART; this quotation from a Namibian woman exemplifies the same concern "with ARVs we can cope with AIDS, but what medicine can you give us so that we can cope with stigma and discrimination?" (Kelly, 2006).

Stigma can put someone in suicide thinking, if not, to commit suicide, because, life seems disgusting. It was the case of this woman explained by an interviewee, who was HIV positive with a husband HIV negative; she has even started an ART but her husband always insults her with neighbors around and she could not endure and passed away.

Nelson Mandela cited by Kelly, (2006) said "many people suffering from AIDS are not killed by the disease itself, they are killed by the stigma and discrimination surrounding everybody who has HIV and AIDS."

We found two type of stigma as described in the literature in our study: felt stigma or perceived-stigma or internal stigma, and the enacted stigma or external stigma that lead to discrimination. In discrimination, you are treated differently very often in an unjust way, because you are seen as belonging to a different group.

Through interviews, we would say that many of those who were taking their medicines secretly have never been victims of stigma or discrimination. Therefore, felt or perceived stigma seems to be higher than enacted stigma.

Ngamini et al, 2006 in their study on stigmatization and adherence to HAART in Burkina Faso and Mali showed that perceived stigma is higher in Burkina Faso (74%) than Mali (60%). They reported that patients with lows levels of stigma were twice more likely to be adherent than those reporting high level of stigma. For them perceived stigma is more frequent among the most vulnerable segments of the population.

Kelly (2006) said that pre-empting the reactions of society, the self-stigmatized person constructs a self image so low in self-esteem that he/she positively cower before the expected comments and behavior of others. The testimony of one participant of the present study illustrated that point. He

mentioned that sometimes, when he is somewhere, he got a feeling that everyone eyes are pointed on him.

In order to avoid stigma and discrimination participants have adopted many coping strategies such as assimilate AIDS to other disease, hiding, pill repackaging.

Therefore, stigma remains high in our context and need to be addressed by taking into account the two aspects of this social phenomenon.

Antiretroviral therapy has permitted PLHIV previously physically incapacitated by the disease to recover. Then, this physical recuperation may reduce (as participants recognized it themselves) enacted stigma of the society from which they are suffering. Therefore, they first need to demonstrate that AIDS is a chronic disease and being infected is not equivalent to death. In addition to that, some behavioral communication change towards the society may contribute to an enabling environment.

However, tackling perceived stigma is a challenge for PLHIV and depends on their willingness to recreate their life with family and community support.

4.7 Family/friend/community support

Family or community members appear to be a major support for PLHIV according to respondents.

Indeed, family throughout children, brothers, sisters, partners and sometimes parents bring morale, material or financial support to PLHIV.

However, the direct support on patient adherence was very often done by children and partners or spouses. The common support was including reminding pill taking time, medical appointment, and drug supply.

Kaai, 2004 in Tanzania found that PLHIV prefer to disclose their HIV status to family members, specifically partners and siblings mainly because of a desire for social and financial support.

Oumar, 2007 in Mali showed that 53% of their respondents were assisted, and the factor associated with a good adherence was the assistance of the patient by a member of the family especially children. Others studies have also reported that children were among the main providers of social support taking a leading role in reminding the parents of pills time (Hardon, 2006; Niamba, 2006).

In terms of community support, the one frequently cited by participants was the self-support group. It is a group or association of PLHIV known as CBO, which is doing many HIV/AIDS-related activities, and the most important was sharing experience on ART. Those who used to participate at these meetings found it, very helpful, an opportunity to avoid loneliness, to get practical information about AIDS and its treatment and to share personal concerns.

However, some participants criticize the self-support groups because of poor fund management, and the risk of disclosure due to certain activities of the group.

Nevertheless, if the leaders of these groups get training, if they get funding and if they are supervised on management process, they may play a major role in treatment program, prevention, and reduce stigma and discrimination within the community.

4.8 Feeling healthy/living for someone

These factors were pointed out as motivators of adherence as showed in the literature (Aspeling, 2006; Hardon, 2006; Diabate, 2007). Nevertheless, in our study we found that better health does not always lead to better quality of execution of treatment. Once healthy, some patients become more and more careless, although they still persistent. Then, what will be the level of adherence for these asymptomatic HIV patients on ART?

4.9 Gender and adherence

Among factors that may influence adherence the common was homelessness. In this Medical Centre, most of the homeless were women, all, victims of discrimination.

Woman, most of the time, is the first one that discover her HIV status in the couple, because of using the antenatal care services within which PMTCT program is implemented; but also as Hardon, (2006), we found that women is more likely to accept her HIV status and seek health care.

Then, once she discloses her HIV status to her husband or family members, one sacks her. It also happens when the family assumes that there is no more means to take care of the person. They just pick her up to the Medical Centre and do no longer ask about her. It is to say that, she got what she was deserved.

Study in Burkina Faso and Mali carried out by Ngamini et al, 2006 found that women, youth and people with low financial status, reported more stigma than men, older, wealthier people. For them, the association between adherence and stigma remained significant once gender was taken into account.

McAllister, 2005 stated that poor housing or homelessness might be of more immediate concern to a patient than adherence. Drenna, (2005) indicated that homeless HIV-positive injecting drug users reported high level of anxiety and stress and depression. For him depression was significantly related to adherence.

In Ghana, Oni, 2005 also mentioned that although patients worried for their health, being accepted by their family remained their principal concern and this psychological stressor was known to worsen health outcome.

Ouagadougou, the town of our study setting, already had a boarding school for women accused of witchcraft and rejected by their community. It implies that, for the same condition, a woman is more « rejectable » than man is. Beyond the care, Pissy Medical Centre patients have other concerns that could hamper them from access to optimal adherence.

Barrier as being away from home and missing dose or drug supply seems to be linked to men. Indeed, considered often in our context as breadwinner in the family, as soon as his health status « allows » him, man travels for job. Then, due to unforeseen reasons, they stay far without medicines. In this study, we found that alcohol abuse was related to men especially if they got healthy. That may inhibit long-term adherence.

The strong child desire among HIV positive women on ART in this study could be a facilitating factor of adherence if there is good patient-provider relationship. As women would like to get child safe of HIV, they will be eager to adhere to their therapy in order to decrease viral load. Unfortunately, these women, impatient or being non-disclosed to their partners got pregnancy and providers are informed later on. Thus, child bearing within a couple which, the woman under ART did not disclose met difficulty to adhere after delivery. The pregnancy may also worsen the immunity system and that can lead to a relapse and thereafter discourage the patient to persist to treatment. A research on the impact of pregnancy and ART adherence should be undertaken.

5.0 Conclusion and Recommendations

5.1 Conclusion

Nowadays, antiretroviral therapy issues increasingly shift from access to medicines to adherence to ART. Adherence to ART is a multifactorial question that requires a multisectoral response. Factors found are interlinked, the ones more directly related to adherence than others did.

From this study, critical barriers to adherence that emerged include illiteracy, religion and beliefs, transport cost, hunger, stigma and fear of disclosure, feeling healthy and gender. Even though illiteracy was cited as barrier, participants have developed adaptation coping strategies to overcome it. Stigma is not a proximal determinant of non-adherence. However, fear of disclosure, privacy needs for pills taking associated with the anticipation of social isolation, loss of support that accompany the stigma tied to AIDS are important factors. Main facilitators of adherence include the acceptance of the disease, patient readiness to start treatment, family/peer-support groups, disclosure, living for someone, religion. It is a paradox, but when people feel healthy, although they ensure the continuation of their treatment, they decrease the quality of execution (not taking on time, skipping dose of medication, failure to comply with dietary requirements).

Disclosure was one of the facilitating factors, although not unanimously recognized by participants as a facilitator. Nevertheless, none of them remains completely non-disclosed. Everybody has disclosed to at least a family member, a friend, colleague or a religious leader... Those who claim their HIV status everywhere like in the media were HIV activists or responsible of association. At least each participant has made a partial disclosure, which they feel was helpful for adherence.

With regard to gender and homelessness of HIV infected women and low utilization of health care services by HIV infected men were perceived as barriers to adherence. However, the fact that homelessness is consistently associated with gender (female) and poverty, does not allow conclusions. The issue of low utilization of care services seems delicate to discuss due to our purposive sampling, which targeted '*successful patients*'. Low utilization of health care services affects likewise the delay in treatment initiation. Further studies are needed.

This study showed that beyond access to ARVs, there are some other issues that may compromise a long-term adherence to ART at the CMA of Pissy. Even though patients use avoidance and adaptive coping strategies to overcome these emerging issues, there are still some issues that need to be addressed if we really want to transform HIV/AIDS into a chronic disease like all the others.

Improving adherence at the CMA of Pissy requires a collaborative approach with the patients, the community, health care providers, and leaders and decision makers.

5.2 Recommendations

The following recommendations are provided to stakeholders involved (communities, providers, decisions makers) in the treatment network in relation to what was found in this study and in order to enhance adherence at the CMA of Pissy.

❖ **People living with HIV**

PLHIV should join as much as possible to existing peer support groups or create new ones in the neighborhood, faith-based or community environment. They should participate actively to the sharing of information and experience, defend their right and fight against stigma and discrimination rather than solely and passively receiving goods and various donations from groups.

The advantages include better treatment literacy, exchange on shared problems and solutions regarding issues in relation to evolving adherence strategies as new needs emerge, child desire, sexuality, etc.

The way forward: such small groups creation could be facilitated by healthcare providers to start and thereafter the group should take responsibility for its own process (link with recommendation to district health management team on support groups)

❖ **Communities**

NGOs, CBOs, FBOs should aside their preventive and spiritual support activities also engaged in treatment adherence support. By encouraging and sensitizing people to accept PLHIV, they contribute to enhance adherence to ART. That may facilitate HIV status disclosure, pills taking, reduce stigma and risk behaviors of non-infected people, as well as PLHIV.

Interventions may include morale and spiritual support to PLHIV in order to restore hope and to fight against morale, social, cultural prejudice social and economic support.

❖ **The CMA of Pissy**

The CMA of Pissy should provide psychological support for patients in need, those who are experiencing "treatment fatigue or drug fatigue" or other emotional barriers should be assisted.

The CMA of Pissy needs to adjust its adherence support program. Indeed, health literacy education is already integrated as part of the patient's overall treatment. However, contain of the offered counseling, does not fit to long-term adherence patients. The issues of drug resistance, late side effects, sexuality should be addressed.

Being the top technical structure (in terms of HIV/AIDS case management) in the district, the CMA of Pissy should accompany Health Centre personnel for the decentralization of ART program. That can reassure patients and help them to build strong relationship patient-providers at this level of the care system.

❖ **MSF**

MSF is a technical and financial partner of the health district. Then, it is strongly involved in the process of decentralization and patient autonomy program. To contribute to ensure adherence over time in this process, MSF in collaboration with the district should solve the issues of drugs supply, laboratory reagent. In addition, they should especially answer the question of continuation of total free ART and ART support services.

❖ **The district Health Management Team**

The district management team should organize a workshop with main stakeholders like PLHIV representatives, NGOs and CBOs that working in the area of AIDS to design a sensitization program on stigma and discrimination. Religious leaders should be involved as well. Themes such as mode of transmission, community/family support to PLHIV on ART, influence of stigma on adherence could be bring up.

They should closely work with MSF, others NGOs and CBOs on decentralization and patient autonomous program to enhance adherence to ART in the district. PLHIV associations should be involved in the process, because of being the first concerned.

They should discuss with the hierarchy and MSF on how to ensure free ART with patient autonomy and decentralization program.

Strengthen peer support groups by documenting processes and outcomes, and share promising practices across groups.

In collaboration with the Health region direction, the social welfare region direction, they should discuss strategies for homeless infected women social reinstatement.

❖ **National AIDS Council/Ministry of Health**

Similarly to what has been done with tuberculosis patients in Burkina Faso, the ministry of Health and the National AIDS Council should bring food support for poor HIV patients on ART during their first year treatment. The World Food Program can be one of the partners.

They should equip, Samandin Health facility laboratory with a CD4 cell count machine in order to reduce distance and patient waiting time for this blood test.

They should promote internal mainstreaming (workplace policy) within the line ministries and others private or para-statal services. This may reduce stigma and discrimination and facilitate adherence.

They should extend within the national ART protocol, the patient's drug supply periodicity, one (1) month to three (3) months for patient who had at least two years treatment. This may ease the patient autonomy program and adherence to ART.

5.3 Limitations of the implementation of the study

The three interviews used per participant were important to verify and to complete data as much as possible. However, it requires typist (secretary) with good level in the language used during the interview as well as for the transcript. The typing has delayed our mid term review.

There is a risk of lost to follow up for the second or third interview. A strong arrangement fro the next meeting should be made with the participant at the end of each interview.

This research requires time and money because of its length (at least tow/three months only for the interview).

5.4 Subject for future Research

- Patient declared having drug resistance to ARVs and Adherence
- Homelessness and adherence to ART
- Child desire: motherhood impact on ART outcome
- Adherence to ART for patients initiated at the asymptomatic stage of HIV infection.
- Roots of Stigma: community understanding of HIV infection and HIV patients
- Forgetfulness and ART (side effect?, natural phenomena?, Lifestyle matter?).
- Contribution of PLHIV on the fight again social stigma

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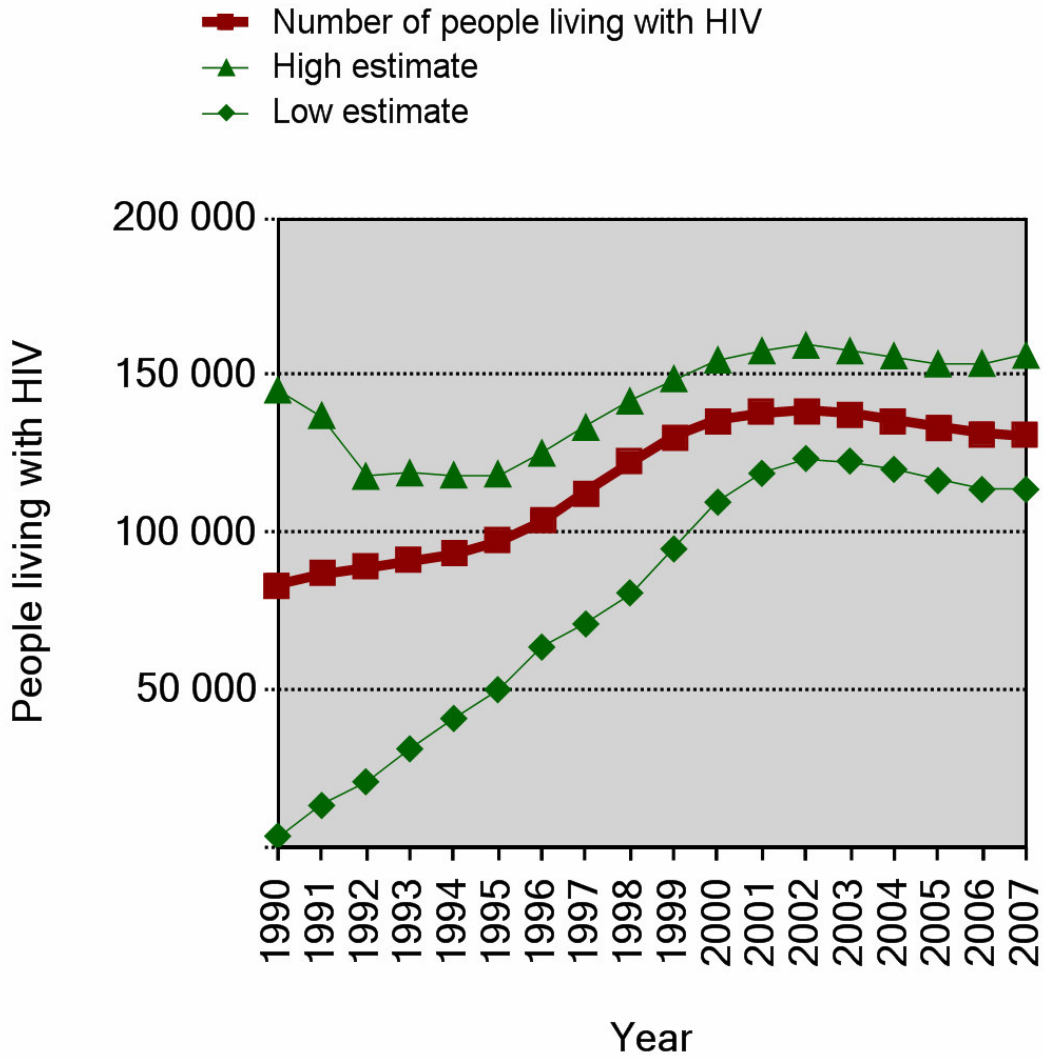
APPENDICES

Appendix 1: Map of Burkina Faso



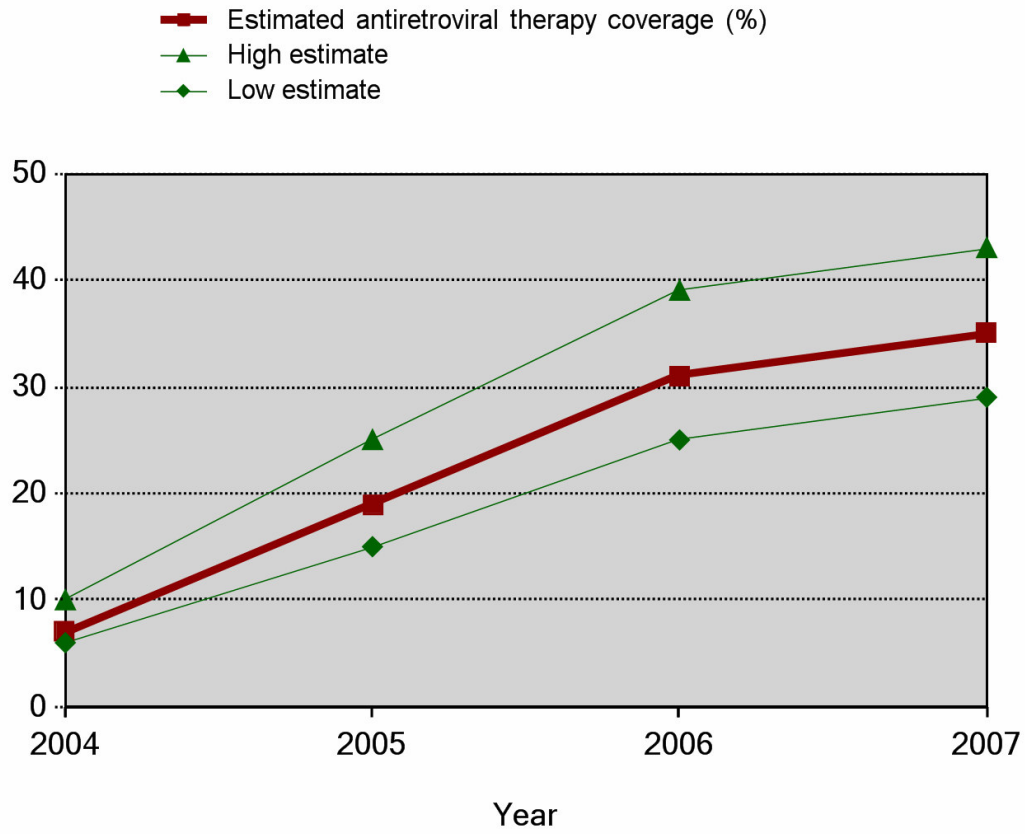
APPENDIX 2: Number of PLHIV

Number of people living with HIV, 1990-2007



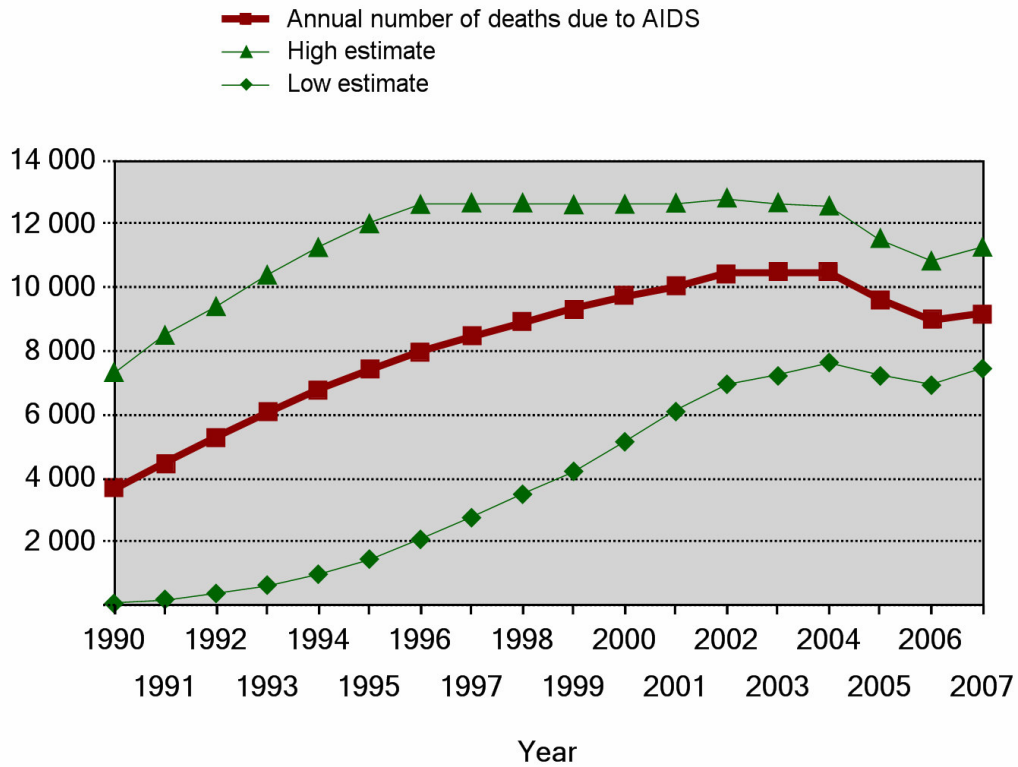
APPENDIX 3 ART coverage

Trends in antiretroviral therapy coverage 2004-2007

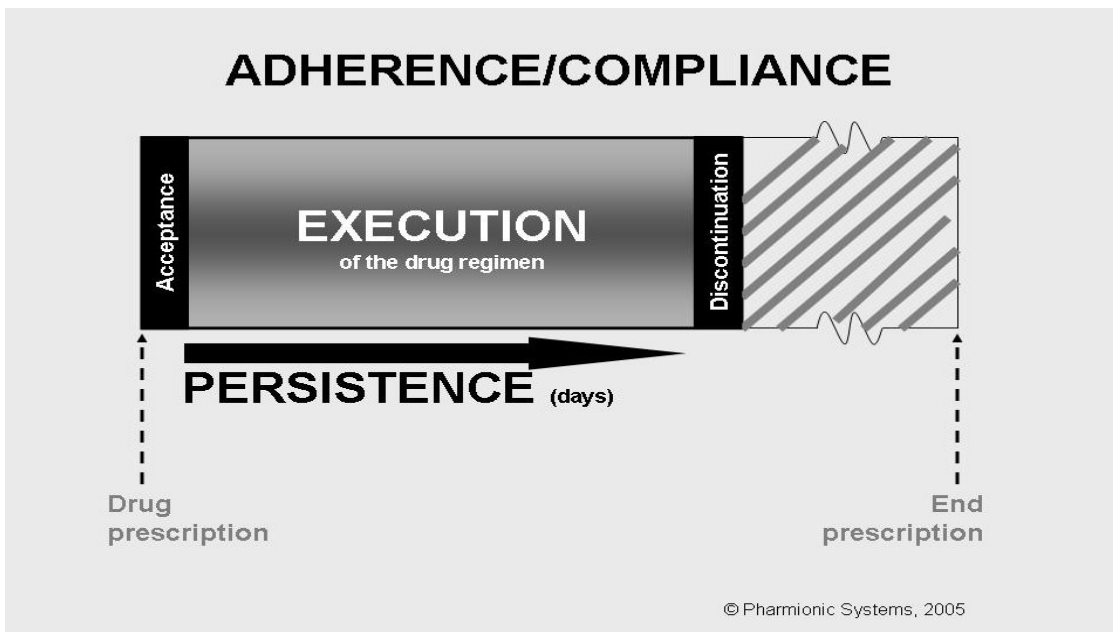


APPENDIX 4: Deaths due to AIDS

Estimated number of deaths due to AIDS 1990-2007



APPENDIX 5: Urquhart and Vrijens model of Ambulatory Pharmacotherapy



APPENDIX 6: Interview guideline

Theme 1: Biography, history and disease treatment

Question: tell me about yourself and your disease as well

Sub-theme 1: Discovery and management of the HIV positive status

- Circumstance of discovery of HIV positive status
- Observed Reaction
- Information sharing
- Reasons of information sharing with the entourage
- Entourage reaction

Sub-theme 2: Main events marking trajectory of life

- Life and professional, social, emotional, sexual experiences
- Number and experiences with the sexual partners

Sub theme 3: Therapeutic itinerary since the discovery of the HIV positive status

- Process, actors and results (treatments and approaches)

Sub-theme 4: ARVs

- Experience and assessment of the ARV treatment, and the services? (Effects on your life, on your relationship, etc.)

Theme 2: Adherence to ART

Sub-theme 1: Acceptance / Appropriation

- Acceptance of HIV infection and ARVs
- Responsibility attribution: oneself, others
- Social effects induce by the ARV treatment

Sub-theme 2: Persistence to ART in the long term

- Biological, social, psychological obstacles
- Biological, social, psychological facilitating factors

Theme 3: Strategies (individual, family, community and institutional)

Sub-theme 1: Experiences with the strategies with the passing of the time: limits/acquisition

Sub-theme 2: Individual strategies

Guideline Details

Thème 1 :	Questions d'ouverture	Types d'informations attendus, ouvertures et relances	Notes pour les enquêteurs
Biographie, Histoire de la maladie et recours thérapeutiques	<ul style="list-style-type: none"> Parlez-moi de vous-même et de l'histoire de votre maladie... 	<p>[Significations, attributions et représentations sur l'infection à VIH, et perceptions sur les ARV, etc.]</p> <ul style="list-style-type: none"> Quand avez-vous commencé le traitement par les ARV ? Comment vous sentez-vous depuis que vous êtes sous traitement avec les ARV ? Vous considérez-vous toujours comme malade ? <p>Récit de vie et contextualisation : Vivre avec le VIH, Vivre avec le SIDA, Vivre avec les ARV.</p>	<p>1. Se présenter soi-même brièvement</p> <p>2. <u>Time Line description</u>: Capter et cadrer les séquences biographiques des patients (lieux, acteurs, événements jugés importants, processus) et les différents moments et contextes clés de l'itinéraire thérapeutique.</p>
Sous thèmes			
1. Principaux événements marquants dans la trajectoire de vie	<ul style="list-style-type: none"> Vie et parcours professionnel, social, affectif, sexuel, etc. Circonstances de la découverte de la séropositivité et vos réactions à l'annonce. 	<ul style="list-style-type: none"> Dites-moi de quelles façons le SIDA a affecté votre vie : manifestations, soutien, stigmatisation, rejet, religion, environnement social et professionnel, etc. Rencontres initiales avec les systèmes de santé [populaire, traditionnel, médical]. Est-ce que vous avez essayé les traitements traditionnels ? <ul style="list-style-type: none"> Acceptation, déni, colère, soutien, etc. Variations selon le Genre, Age, TEMPS : Localisation de la responsabilité de l'infection soi même? autrui? Partage de l'information ou non, Raisons de partage de l'information ou non; Réactions de l'entourage. Variations selon le Genre, Age Recours thérapeutiques et Début du traitement par ARV : circonstances, acteurs, démarches, processus, [des démarches et des soins / traitements reçus] 	<ul style="list-style-type: none"> Périodes, lieux, acteurs: automédication, Conseils de proches, Tradipraticiens,? Variations selon le Genre, Age <p>RESPONSABILITE N'EST PAS CUPABLE</p>
2. Découverte et vécu [gestion] de la séropositivité	<ul style="list-style-type: none"> Parlez-moi de vos expériences de vivre avec le VIH/SIDA Localisation de la responsabilité de l'infection soi même? autrui? 		<ul style="list-style-type: none"> Explorer les connaissances et sens donnés aux examens bio [charge virale, CD4, etc]
3. Itinéraire thérapeutique	<ul style="list-style-type: none"> Parlez-moi des traitements que vous avez suivi depuis que vous avez ressenti que quelque chose n'allait pas. 	<ul style="list-style-type: none"> Pouvez-vous comparer les traitements ARV avec ces traitements ? [Perceptions sur les traitements au long cours] Quelles ont été les effets des traitements ARV sur ta vie, tes relations, etc? Est ce que ces traitements affectent vos activités quotidiennes? Besoins évolutifs en soins et soutien et utilisation / satisfaction avec les services [Avez-vous pensé à rejoindre une association ? En connaissez-vous ? Comment ?] Soutien informel [famille, amis, pairs, etc] Evolution des perceptions et des sentiments sur la maladie, le mal, etc. 	<ul style="list-style-type: none"> Explorer la perception de différents modèles de traitements traditionnels u médicaux avec le traitement ARV. Dimension temps
4. Traitements antirétroviraux	<ul style="list-style-type: none"> Avez-vous l'expérience d'autres traitements traditionnels ou médicaux longs ? Parlez-moi de vos expériences avec le traitement ARV et avec les structures de prise en charge 		
Thème 2 :	Questions d'ouverture	Types d'informations attendus, ouvertures et relances	Notes pour les enquêteurs
Observance ARV	<ul style="list-style-type: none"> Vous êtes sous traitement depuis plus de 3 ans. Racontez-moi votre vie avec les ARV. 	<p>Quelles sont les difficultés que vous avez rencontrées avec votre traitement ?</p> <ul style="list-style-type: none"> Qualité de la mise en œuvre du traitement Persistance dans la poursuite du traitement Besoins évolutifs en soutien Apports et limites des stratégies de gestion du traitement 	
Sous thèmes	<ul style="list-style-type: none"> Acceptation du 	<ul style="list-style-type: none"> Localisation de la responsabilité de 	

<p>1. Acceptation et Appropriation du traitement</p> <p>2. Persistance ou observance à long terme [Entretien]</p>	<p>traitement</p> <ul style="list-style-type: none"> • Place sociale des ARV • Effets et adaptations quotidiens ou circonstanciels induits par les traitements ARV • Arrêts du traitement / Reprises du traitement [fatigue? Autres circonstances ?] • Bénéfices et Obstacles [biologiques, psychologiques, sociaux] 	<p>l'infection soi même? autrui? [Devenir ACTIF dans son traitement]</p> <ul style="list-style-type: none"> • Acceptation de l'infection, autres facteurs explicatifs [religion] • Comment est ce que vous organisez votre quotidien avec le traitement ? Pendant le jeun du mois de Ramadan (Musulmans) ou le carême (Chrétiens) ? • Perceptions sur le bénéfice des traitements [Anecdotes] Nouvelles perspectives de vie ? Perceptions sur le désir, renoncement à la sexualité, à l'enfant ? • Evolution sous traitement et perceptions sur la nécessité de poursuivre le traitement malgré un état de bonne santé apparente [Anecdotes] • Dépression, épisodes de vie ? Fatigue du traitement • Perceptions sur les effets secondaires [Sensation de faim, Anecdotes] • Perceptions sur les effets de l'accompagnement thérapeutique par un proche de la famille 	<ul style="list-style-type: none"> • Variations selon le Genre, Age • Décalage entre non observance du traitement et conséquences ? • La question de la confiance dans le médecin, remise en question d'un protocole thérapeutique, dont l'efficacité se trouve dans certains cas mise en question.
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Thème 3 :	Questions d'ouverture	Types d'informations attendus, ouvertures et relances	Notes pour les enquêteurs
<p>Stratégies d'appui à l'observance des ARV</p>	<ul style="list-style-type: none"> • . Disqualification des stratégies et modes de gestion du traitement • Pouvoir Médical 	<p>Quelles sont les difficultés que vous avez rencontrées avec votre traitement ?</p> <ul style="list-style-type: none"> - Qualité de la mise en œuvre du traitement - Persistance dans la poursuite du traitement - Besoins évolutifs en soutien - Apports et limites des stratégies de gestion du traitement - Cohérence des interventions des différents prestataires 	<p>Distanciation</p>
<p>Sous thèmes</p> <p>1. Expériences avec les stratégies d'appui à l'observance au fil du temps</p> <p>Stratégies Individuelles</p>	<ul style="list-style-type: none"> • Perceptions sur les stratégies d'appui à l'observance [processus, acteurs, contenus]. Parlez-moi des médecins, des autres soignants, des services que vous avez fréquentés ? • Avant : tenir la main accompagnement de personnes en fin de vie. RUPTURE : nouvelles perspectives 	<ul style="list-style-type: none"> • Perceptions sur les effets de l'accompagnement thérapeutique par un proche de la famille • Au fil du temps et à des moments particuliers vous avez rencontré des difficultés avec le traitement [voyage, stigma, oubli, effets secondaires, restriction diététiques et fêtes, maladie opportunistes, etc.] • Dans ces situations, vers qui vous êtes vous tourné ? • Qu'est ce qui s'est passé ? Résultats du recours ? • Evolution de la relation avec les systèmes de soins [acquis / limites] • Evolution de la relation prestataire - prestataire [collaboration? acquis / limites] • Apport des prestataires : Evolution de la relation soignant – malade, Différentes stratégies de soutien [Anecdotes], acquis / limites • Apport de la famille : Différentes stratégies de soutien [Anecdotes], acquis / limites <p>Stratégies personnelles : Anecdotes, acquis / limites</p> <ul style="list-style-type: none"> • Capacités (forces) d'innovation et de résolution des problèmes • Réseau social [mapping : Portait du réseau social • Genre 	<ul style="list-style-type: none"> • Variations selon le Genre, Age AUTRES : Milieu Professionnel Apports et limites • La question de la confiance dans le médecin, remise en question d'un protocole thérapeutique, dont l'efficacité se trouve dans certains cas mise en question.

APPENDIX 7 Consent Form

Je soussigné (e), donne mon accord pour participer à l`enquête sur l`observance des traitements antiretroviraux (ARV)

J`ai été informé (e) des faits suivants :

- l`enquête consiste en 3 ou quatre entretiens,
- j`ai le droit de ne pas répondre aux questions qui me sont posées
- mon nom n`est pas enregistré et aucun élément permettant de me reconnaître ne sera dévoilé,
- les personnes qui réalisent cette enquête sont tenues au respect du secret professionnel,
- cette enquête est indépendante des services de soins et des projets de recherche auxquels j`ai participé jusqu`à présent,
- elle consiste à répondre à des questions, mais ne comprend aucun acte médical (consultation, prélèvement, soin)
- dans le cas où cette enquête ne se déroulerait pas correctement, il m`est possible d`en informer une association ou une autorité compétente,
- j`aurai accès, si je le désire, au rapport final de la recherche,

Bobo-Dioulasso/Ouagadougou, le.....

Signature

