Experiences and expectations of Sub-Saharan HIV positive patients with Primary Healthcare in Belgium:

An interview study with Sub-Saharan African Migrants

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Abstract

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Topic: Experiences and expectations of Sub-Saharan HIV positive patients with primary health care In Belgium: an interview study with Sub-Saharan migrants.

Background: Africa is a continent that has been heavily affected by HIV. The worst epidemics in Sub-Saharan Africa are in East and South Africa. The rapid increase in Sub-Sahara can be explained by a complex interplay of sexual behavior that is influenced by the cultural and socio-economic context. In Belgium, and Europe too, the problem is increasing due to the increase in population of migrants from Sub-Sahara and men who have sex with men. In Europe, Belgium has one of the best concrete HIV treatment plans. Most patients are treated in the second line, namely in Aids Reference Centers such as the Institute of Tropical Medicine. In the last years, the availability of highly active antiretroviral therapy, continuity of care and good follow up of the patients have led to increased life expectancy and better life quality, hence chronic care. The most important persons in primary care for the follow up of these patients are the General Practitioners. There are though some challenges which make it impossible for GP's to take full responsibility of the follow up.

Objectives: In the past years, master theses have explored the attitudes of General Practitioner's towards HIV care in Belgium. Here homosexuals and Sub-Sahara African migrants are the biggest groups of seropositive patients. Some studies have already explored the perspectives of seropositive homosexuals, but there is still a need to study the perspectives of the second group. The aim of this master's thesis is to question Sub-Saharan seropositive migrants about their experiences and expectations related to Primary Health Care and in particular about their treatment and follow-up by general practitioners.

Research questions*:* What are the experiences and expectations of Sub-Saharan HIV patients towards Primary Health Care? Are the treatment and counseling of HIV-positive migrants of Sub-Saharan origin suitable for GP's in Belgium?

Research area: GP's care for HIV-positive patients of Sub-Saharan African origin, not anymore in the start-up phase of their treatment, but with a stable disease and older than 18 years.

Language usage: English, French, Dutch, and Swahili.

Results: Eight participants of Sub-Saharan origin, both males and females, were open to tell their views on their HIV care while staying in Europe. Everyone appreciated the Health Care System and was thankful for escaping death. 99% of them had a permanent GP, being constantly in contact with a Aids Reference Center. Trust and confidence was only built after long time of sharing. Few of them experienced discrimination indirectly or directly. It was challenging that not all their problems could be solved at the Aids Reference Centers. Due to short consultation times, they could not share enough information with the specialist at these Centers. GP's had more time to listen to their problems and solve them, but they felt there was not enough protection of privacy concerning their disease at the GP's offices. How to age with HIV was another concern among the participants.

Conclusion: The main follow up of these patients, including keeping records about their HIV status, remained safe at the Aids Reference Center, but chronicity and increased life expectancy made it impossible for Sub-Saharan HIV patients to get their follow up at the Aids Reference Centers alone. GP's should be the most important health care workers in the follow up, but the disclosure problem still needs to be solved. GP's must be equipped to take partly and if possible complete care of the patients with good secured and centralized data. GP's have also to accept that they cannot work without being daily confronted with Sub-Saharan HIV patients. Future studies and help by the Belgian Health Care System are required to make all this possible.

Abbreviations List

AIDS: Acquired immune deficiency syndrome

ARC: Aids Reference Center

CD4: Cluster of Differentiation 4

ECDC: European Centre for Disease Prevention and Control

HAART: Highly active antiretroviral therapy

GP: General Practitioner

HIV: Human immunodeficiency virus

ITM: Institute of Tropical Medicine (Antwerp)-ITM

MSM: Men having sex with men

PHC: Primary Health Care

PITC: Provider-initiated HIV testing and counseling

HIV MTCT: HIV mother-to-child transmission

SAM: Sub-Saharan African Migrants

SSA: Sub-Sahara Africa

OCMW: Openbaar Centrum voor Maatschappelijk Werk: Public Social Welfare Office

PrEP: Pre-Exposure Prophylaxis

1. Introduction

1.1. Background

Africa is one of the continents suffering under a serious HIV-epidemic today. However, the HIV rate has decreased due to ongoing treatments and prevention measures done for years. Since the beginning of the epidemic, more than 70 million people have been infected with the HIV virus and about 35 million people have died of HIV. Overall, 36.9 million [31.1– 43.9 million] people were living with HIV at the end of 2017. An estimated 0.8% [0.6-0.9%] of adults aged 15 – 49 years worldwide is living with HIV, although the burden of the epidemic continues to vary considerably between countries and regions. The African region remains most severely affected, with nearly 1 in every 25 adults (4.1%) living with HIV and accounting for nearly two-thirds of the people living with HIV. (1, 2)Historically there is a great evolution on HIV disease since 1980's.

Despite all the measures taken in Belgium by the country's public authorities, HIV remains a major Public Health issue. At least 20,000 people are living with HIV and between 1,000 and 1,200 new cases are diagnosed annually. Belgium is one of the European states with the highest number of diagnosed infections: 10.7 cases per 100,000 inhabitants in Belgium compared with 5.7 cases on average in Europe in 2011). (3)

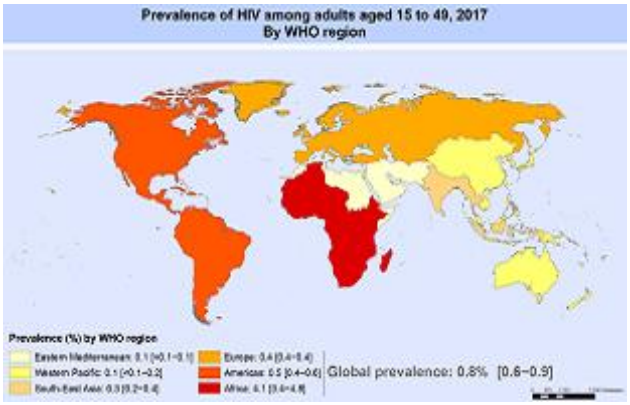


Figure 1: HIV worldwide. Number of cases in 2017 (Global Health Observatory 2017)

Migration is a key to the spread of HIV. It has however to be approached carefully, with no condemnation. People have a right to move and the consequences of migration vary from country to country. The link between migration and HIV is crucial. From the 36 million people estimated to be living with HIV, 95% of these infections have occurred in developing countries with poverty and insufficient health systems. (4)

Migrants account for 35% of HIV diagnoses in the European Union. (5) There is a high rate of migration and about 125 million people live and often work outside of their country of citizenship, while between two and four million people migrate permanently each year. As of 2017, 65.6 million individuals have been forcibly displaced worldwide because of persecution, conflict, violence, or human rights violations, according to the UN High Commissioner for Refugees. (6)
In 2014 studies showed that 57.1% of newly diagnosed HIV-infected women in Spain were immigrants, mainly from SSA and Latin America. (7)

Migrants from high endemic regions, including those from Sub-Saharan Africa are the second largest group affected by HIV/AIDS in the European Union/European Economic Area (EU/EEA) and a priority group for HIV prevention. (8) In 2014, 13.8% of new HIV diagnoses in EU/EEA Member states were among Sub-Saharan African migrants. Since 2005, surveillance data show a decreasing trend of HIV diagnoses among this group. (8)

In 2014 mathematical modeling estimated, that among 15-44 year old black heterosexual Africans 17.9 per 1,000 men and 43.7 per 1,000 women were living with HIV in the United Kingdom. (9)

Migrant populations have a greater risk for poor health in general and HIV infection in particular. (10) This is due to the impact of socio-cultural patterns of the migrant situation on health, their economic transitions, reduced availability and accessibility to health services and the difficulty of the host country's Health Care Systems to cope with the traditions and practices of the immigrants. (10-12) The otherness of migrants often creates xenophobia, isolation and hostility by the host community. In addition, as with other people living with HIV/AIDS, migrants who are HIV-positive, are subject to stigmatization and discrimination, and therefore, they hide their HIV status as long as possible, thus making support services unavailable for them. (10)

In Switzerland studies revealed that, the rate of HIV-positive test results from Sub-Sahara migrants has increased from 4.5% in 1988 to 37% in 2005. (13, 14)

The introduction of antiretroviral therapy caused a revolutionary change in HIV/AIDS. Due to early treatments and good follow up, it has now become a chronic disease. Worldwide, there is growing evidence that primary health care is the key component of chronic disease management. In Belgium specialists in the AIDS reference centers still take care in most cases of HIV/AIDS and only few General Practitioners are actively involved in HIV care. Because this disease is becoming a chronic condition, GP's will be more confronted with chronically ill and older patients with HIV/AIDS. (15)

1.2. Research questions

The purpose of this study is to explore HIV care in Primary Care, with the aim to improve care on the longer term.

The main research question is: What are experiences and expectations of Sub-Saharan HIV patients with Primary Care?

Sub-questions are: Are treatment and counseling of HIV-positive migrants of Sub-Saharan origin part of the tasks of GP's in Belgium? How was the accessibility for care among the Sub-Sahara Migrants with HIV in the past years?

The aim of this master's thesis is: to perform a literature study and to interview Sub-Saharan seropositive migrants about their views in relation to the treatment and follow-up of their specific state of health by general practitioners.

2. Literature study

2.1. Introduction

This literature study tries to give an overview of the situation of HIV-care for Sub-Sahara migrants in Belgium and Europe. What do Sub-Sahara HIV patients expect about primary health care in Belgium?

The first aim is to explore the situation and existing care of patients in the European countries and especially in Belgium. Migration as a process has an effect in the spread of the disease. How is the care of SAM migrants in western countries organized? Is care easily available for these people? GP's are the most important group in the Primary Health Care settings in Europe. Belgium can be used as a country of reference, where HIV care is highly developed, particularly amongst the SAM group. Much work and follow up has been done with the Institute of Tropical Medicine of Antwerp, being the biggest ARC and the best known European Institute for Tropical Diseases.

What are the attitudes of General Practitioner's towards HIV-care? Currently studies have been done in Belgium about patients' perspective of seropositive homosexuals. Sub-Sahara African Migrants and homosexuals form the biggest groups of seropositive patients in Belgium. There is a need to study SAM patients' perspective.

2.2. Methods

Search strategies: The first literature search was done in September 2018 and from January to March 2019. More literature was added to the research work through searching, by using existing International Guidelines, National Guidelines, Pub Med, Medline, EBM practice Net, NHG, Domus Medica, Cochrane Systematic Reviews and Google Scholar for relevant articles and information. A total of 56 articles were identified and two important Master Thesis's from Dr. Katleen Verheyen, and Dr. Sarah Swannet were read with interest. The information related to

objectives of the study, was selected and summarized in a thematic way. Later the articles were ranked according to the ones with most important information ready to be used. Non-selected articles were left for further use whenever necessary.

Search Terms: HIV and Sub-Sahara Africa, HIV care, Sub-Sahara migrants, HIV and General practitioner, HIV in East and South Africa, HIV and Sub-Sahara Migrants in Europe, HIV and Sub-Sahara Migrants in Belgium, HIV and Migration, HIV in Uganda.
(((((("Africa, Eastern"[Mesh]) OR "Uganda"[Mesh]) OR "Africa South of the Sahara"[Mesh]) OR Sub-Sahara Africa) OR Uganda) OR (((African Migrants) OR Sub-Saharan migrants) OR Sub-Saharan African migrants))) AND (((((((hiv) OR hiv aids) OR "HIV"[Mesh]) OR aids) OR "Acquired Immunodeficiency Syndrome"[Mesh])) AND ((((("General Practitioners"[Mesh]) OR "Physicians, Primary Care"[Mesh]) OR "Family Practice"[Mesh]) OR "Physicians, Family"[Mesh]) OR general pract*) OR primary care*)),
"General Practitioners"[Mesh] "Physicians, Primary Care"[Mesh] "Family Practice" [Mesh] "Physicians, Family"[Mesh], general pract*, primary care

Inclusion and exclusion criteria:

Inclusion Criteria	**Exclusion Criteria**
General practitioner	Medication
Primary Health care	Antiretroviral drugs
Full text	Complications
HIV and Sub-Sahara Migrants	Literature older than 15 years
HIV in Europe	full text not available in English or Dutch
HIV in Belgium	
Literature from now to younger 15 years	
English and Dutch	
Specific guidelines	

2.3. Results

Current prevalence of HIV with Sub-Saharan African migrants in Belgium and Europe:

Sub-Saharan African migrants are the second largest group affected by HIV in Europe. (8) ITM studies in Belgium proved that the general HIV epidemic in Africa declares the high epidemic of African community in Belgium. Although the number of African migrants is only 0.65% of Belgian population, they represent 33.4% of all HIV diagnosis. (16) The proportion of newly diagnosed cases in people of Belgian nationality increased between 2002 and 2011, rising from 29.3% to 42.7% of patients where the nationality is known. Among the non-Belgian patients diagnosed between 2009 and 2011, 62.1% originated from Sub-Saharan Africa, the highest proportion observed in Europe. Mode of transmission is mainly heterosexual for SAM people. The number of infections diagnosed amongst MSM varied depending on their origin: it was 60.4% in nationals from European countries other than Belgium, 61.4% among those from America and Asia, 35% for those from North Africa and 3.9% in people originating from Sub-Saharan Africa. The male/female ratio among non-Belgians is much closer to unity than for Belgians: 3.17%. HIV incidence is more than 3 per 100 people per years in the absence of PrEP for MSM, transgender women, heterosexual women and men who have sexual partners with undiagnosed or untreated HIV infection. (17)

In Belgium 27% (n=230) of the newly reported HIV diagnoses in 2013 were in individuals of Sub-Saharan African origin. In 24% of all reported cases data on the country of origin were missing. Therefore it is assumed that the overall number of new HIV diagnoses among SAM might be underestimated. Yet, it is clear that as communities of SAM are small, 1.6% of the Belgian population, HIV disproportionately affects them. (18)

Early testing is important for African people who are mostly passive in health matters. They act faster when external force acts on them, i.e.: “the doctor decides for me attitude”. (16)

One of the studies revealed that lack of political will, restrictive immigration policies and the absence of African representation in decision-making processes are also major factors preventing black Africans from testing. Most patients postponed testing due to fear for diagnosis of a deadly disease. Other factors for delayed testing are: HIV related stigma, discrimination, isolation, lack of language skills and low educational standards. This delay facilitates a high spread of HIV amongst this group of migrants. People, who are still in the long immigration

procedures across Europe, are difficult to reach by health care givers. This group is dangerous and vulnerable due to undiagnosed cases, which can contaminate other people in the community. (19-22)

Studies done across Europe, mainly in Belgium, Germany, Greece, Italy, the Netherlands, Portugal, Spain, Switzerland and United Kingdom revealed that 83% of both, heterosexual women and gay/bisexual men with permanent residence in one of these European countries, have access to the Primary Health Care. (23)

Studies in Belgium revealed high prevalence of HIV in African Communities. The high epidemic of HIV in Africa correlates with a similar high incidence in African community in Belgium. Even though the number of African migrants is only 0.65% of Belgian population, they represent 33.4% of all HIV diagnosis. (8, 16)

“A study done in 2000 in Spain added the prevalence of HIV was not ably higher among heterosexual persons from Sub-Sahara Africa than from other places of origin, Of the 8861 Subjects included in the study, 2810 (31.7%) came from countries other than Spain. The commonest region of origin was Latin America (73.1%) followed far behind by Western Europe (9.1%), Central and Eastern Europe (6.2%), Northern Africa (4.4%) and Sub-Sahara Africa (4.2%). In This study MSM and heterosexual’s men and women from sub-Sahara Africa were most affected.” (24)

Morocco is considered a transit country for African Sub-Sahara Migrants on their way to European countries. Studies conducted in Rabat have shown a dramatic increase of migration from Sub-Sahara Africa during the past decade. It is a very vulnerable population with irregular administrative situations, in particular poor socio-demographics, bad sexual and HIV testing behaviors and with a high HIV and syphilis prevalence. Roughly 3% of Francophone and Anglophone migrants were infected with HIV. Females were found to have HIV infection rates three times higher and past year sexually transmitted infection signs and symptoms more than two times higher than their male counterparts of the same origin. (25)

In the UK a study showed the rate of mother-to-child transmission within the group of HIV-infected pregnant women fall below 0.5%. In recent years, notably, three-quarters of this population were women from Sub-Saharan Africa. Sub-Sahara Africans have high numbers of incidence even from MTCT. (2, 7)

High number of undiagnosed HIV cases: Although the number of HIV is well estimated, there is still a risk of a group of undiagnosed people. Many people who are HIV positive are unaware of their infection status. Estimation of the number of people with undiagnosed HIV within a country or region is vital for understanding future needs for treatment and for motivating testing programs.

The recommended minimal case reporting data, needed to estimate the number of patients with undiagnosed HIV, are the HIV diagnoses, including CD4 count at diagnosis, whether there has been an AIDS diagnosis in the 3 months before or after HIV diagnosis and data on deaths in people with HIV. Studies have shown many undiagnosed cases in different European countries. (3, 20, 21, 26)

In a study done in Belgium among 744 migrants with HIV, there was a high lifetime HIV testing level in the community of about 73%, while 65.2% of Sub-Saharan African migrants were possibly undiagnosed. (8)

Studies done in Antwerp showed that HIV tests among SAM are not always effectively done. Currently diagnostic and preventive opportunities are missed, due to the fact that, when reported, HIV testing uptake was high among Sub-Saharan African migrants in Antwerp city (i.e. 73.0% reported lifetime testing and 40.4% in the last year). Potentially 65.2% of those found positive were undiagnosed before the study. This indicates that current HIV testing efforts might not reach the sub-groups at highest risk. 3.5% (N = 28) of Sub-Saharan African migrants reported a sexually transmitted infection diagnosis in the last year and 3 of them among people with an undiagnosed HIV-infection. (8)

The United States Agency for International Development has developed a strategic plan to end HIV in the coming years. The aim is to build a new narrative on HIV treatment and a new, final, ambitious, but achievable target. The goal is: by 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression. (27)

Late presentation of HIV cases in Europe: Across Europe almost one third of individuals infected with HIV, do not enter Health Care until late in the course of their infection. (28) Late diagnosis results in delays in initiating treatment and is associated with higher rates of AIDS related morbidity and mortality, higher health care costs and higher transmission rates. (29)

“Late-presenting means persons presenting for care with a CD4 count below 350 cells/mL or presenting with an AIDS-defining event, regardless of the CD4 cell count. Presentation with advanced HIV disease: persons presenting for care with a CD4 count below 200 cells/mL or presenting with an AIDS-defining event, regardless of the CD4 cell count. (28) When reporting late presentation, it is found that SAM are one of the risk groups for late presentation of HIV due to several factors. Late diagnosis was common for women and heterosexual men (60.8% and 67.1%, respectively) despite utilization of health services prior to diagnosis.” (23, 28, 29)

Organization of HIV care for Sub-Sahara migrants in western countries

Availability for HIV care in primary care:

European Health Care System is very advanced and mostly well-organized. Taking Belgium as an example, almost everyone is covered with the Health Care System and an estimated 94% of the population is registered with a regular GP. (15)

People unregistered with a GP can be referred to Second and Third Line Health Care. Nevertheless, there are some areas of improvement when it comes to HIV among SAM in all countries. The Belgian HIV epidemic is largely concentrated among men who have sex with men and Sub-Saharan Africans, the second largest group. (15, 18, 19)

The continuum of HIV care in Belgium presents low attrition rates over all stages. Studies revealed that of all HIV diagnosed patients living in Belgium in 2011, an estimated 98.2% had admittance to HIV care, 90.8% were retained in care, 83.3% received antiretroviral therapy.(15) The undiagnosed HIV-infected population, although not precisely estimated, but probably close to 20%, based on available survey and surveillance results, could be the weakest stage of the continuum of HIV care. Its identification is a priority along with improving the HIV care continuum of migrants. (15, 20)

SAM are the most vulnerable people. Belgium has made it possible for migrants who still have no registration in the government, to receive Health Care for acute problems, but in case of HIV positive cases, the continuity should not only be determined by attending ARC’s, but also by monthly GP follow up. Number of people fall into the category of undiagnosed due to lack of registration. It is impossible for migrants without papers to show up. In this case GP’s are important contact persons, where these migrants can go for help. (30) Cultural, social and

structural barriers to testing, such as access to testing and care, fear of death and disease and fear of stigma and discrimination in the community, can be identified among SAM people. This can hinder them from attending the well-developed Health Care Systems. (10, 19, 31)

Feasibility of HIV Test:

Many European countries, including Belgium, have made HIV tests available and possible amongst the high-risk groups. The HIV Indicator Diseases across Europe Study 1 or Indicator Condition Guided HIV Testing is on of Public Health Initiatives across Europe. The health care providers were encouraged to offer more tests to patients based on suspicion of HIV. This HIDES study provided evidence on HIV prevalence for various conditions and diseases with HIV association. (22, 32, 33)

In a study conducted from October 2009 until February 2011, individuals with an unknown HIV status, presenting with one of sexually transmitted diseases were offered an HIV test. Additional information was collected on previous HIV testing behavior and recent medical history. A total of 3588 individuals from 16 centers were included. Sixty six tested positive for HIV, giving an HIV prevalence of 1.8% [95% CI: 1.42–2.34]; all eight ID exceeded 0.1% prevalence. Of those testing HIV positive, 83% were male, 58% identified as MSM and 9% were intravenous drug users. Twenty percent reported previously having potentially HIV-related symptoms and 52% had previously tested HIV negative (median time since last test: 1.58 years); which together with the median CD4 count at diagnosis (400 cell/uL) adds weight to this strategy being effective in diagnosing HIV at an earlier stage. A positive test was more likely for non-white individuals and MSM. Non-white individuals fall in the group of migrants who are at high risk. (22)

Social cultural attitudes towards the test

Fear of being tested: Africans don't ask the test themselves. In the studies only three out of five Africans have ever undergone HIV test. Most of them are due to initiative of a physician, during prenatal care and pre-operative general examination. Africans don't ask their physician to perform the test, because they are afraid of the results. (16)

Misconceptions: For many African people HIV diagnosis is equivalent to quick death; social isolation and stigma. Many people go into depression after diagnosis if no correct management and advice is provided. (16)

Communication difficulties: Africa is a big continent with many different countries. There are many ethnic groups of which each of them has different culture, religion and level of education. All these factors make communication and understanding of HIV to be approached differently for each individual. GP's have to be aware of these cultural differences in dealing with their patients. (16)

Long-term care in European countries

A Belgian study has illustrated experiences of SSA migrant women living with HIV. Living with HIV and AIDS changes everything for people diagnosed with HIV and it can be the most difficult experience in life. Like most people who have chronic diseases, HIV patients want to live a normal and good-quality life. (34)

The same authors used individual stories to raise questions about the larger context after a HIV diagnosis. (35) Anxiety, depression, fear of stigma, societal gender norms, and support are the related problems. The participants reported that marriage was no guarantee of staying HIV-free, especially in a male-dominant culture. This case further illustrates that both, married and unmarried, African women are often at high risk of HIV and also informs us how HIV could spread, not only because of cultural practices, but also because of individual behavior and responses to everyday life situations. One of the participants also emphasized that she is faced with physical and mental health problems that are typical of people living with HIV. The vulnerability of Sub-Saharan African women to HIV infection and their precarious health-related environments, wherever they happen to be, is further elucidated by this case. There is a need to deal with ongoing long-term problems of HIV positive SAM people. (35)

GP/ARC, PHC position in the Chronic Care of SAM HIV Patients

HIV in Europe remains a Primary Health Care problem. In the UK study of 10612 heterosexual adults born abroad, included in the analyses, 85% (9065) were of black-African ethnicity. It was estimated that 33% (26–39%) of the persons acquired HIV while living in the UK. This percentage increased from 24% (16–39%) in 2004 to 46% (31–50%) in 2010 ($P < 0.01$). The estimate of 33% is three times higher than national estimates of HIV acquired in the UK based on clinic reports (11%) ($P < 0.01$). (36)

Another study done in Belgium showed, that due to chronicity of HIV infection there are more associated comorbidities, because many patients are living longer. The number of patients treated at ARC increased daily. Patients may go at ARC once or twice a year. Someone needs to take care of the other ongoing health problems in their lives. This study indicated the need to share the care of these HIV patients with GP's. The Belgian GP's are motivated to take part of the follow up, but there is need of knowledge structure and protocol. (37)

A study in UK showed that ongoing education is necessary due to chronically ill HIV patients. Over the course of the last 3 decades, it has become clear that education has considerable potential to prevent HIV infection, as well as to mitigate the impact of the epidemic on affected individuals and communities. The world we now live in is not the world that was there at the start of the epidemic, and education - like all practices of care - must orient itself toward the future. How it does this, in what ways, and with what effects, are matters that concern us all, not just as educators and intervention scientists, but as citizens in an increasingly globalized world. This includes educating also the professionals, including GP's. Continuity is needed whereas GP's play a central role in the community. Specialists at ARC are meant to evaluate only the progress of the diseases, whereas GP's take care of the patient globally. This concept must be understood. (9)

Challenges in the European Care System and Social Sector for SAM HIV patients

A French study observed that some of Sub-Saharan migrants leave their network/relatives' accommodation when they are diagnosed. The study clearly showed that this change of residence is linked to starting a partnership and moving in with their partner rather than suffering from negative reactions from their social network. Patients also prefer to start new relationships and sometimes hiding their current situation. (38)

In Belgium, a study done among women of Sub Sahara origin showed that the HIV positive status disclosure is vital for health promotion, social support, wellbeing and the prevention of the disease. This is still a problem amongst SAM HIV positive migrants. Most people keep this disease as a secret. The caregiver's role is vital and therefore HIV disclosure should be systematically incorporated into HIV post-test counseling and primary care services. Problems related to disclosure are such as intimate partner violence, abandonment, humiliation and rejection. There is still growing concern over the rise in new cases of HIV diagnosed in the

European Union, as stated by the European Centre for Disease Prevention and Control. (21, 39, 40)

Another study in France declared that, disclosure in migrants from SSA has been successful amongst SSM living in France with HIV positive and undetectable viral load. Interventions targeting this population should be provided to improve disclosure, which in turn ensures better social support, testing of the partner and lower rates. (31)

To estimate rates and identify correlates of HIV disclosure in migrants from SSA successfully treated, a sub-analysis was conducted in HIV1 native SSA migrants, living in France with undetectable viral load on antiretroviral, included in a HIV adherence study. Logistic regression models assessed factors associated with HIV disclosure. Among 40% male individuals with median age 41 (n = 246), 79% of those in a steady heterosexual partnership (n = 167) had disclosed their status to their partner, 55% of the total 246 to a relative, and 33% to (an)other person(s). Disclosure to one's steady partner was associated with a follow-up duration since HIV diagnosis of more than 5 years, a higher literacy level, a better social context and marital status. Women were more likely to disclose their HIV status to relatives. (21)

2.4. Expectations of Sub-Saharan HIV patients about Primary Health Care in Belgium

The TOGETHER Project was conceptualized to respond to the growing need for investing in targeted primary prevention interventions to reduce new HIV infections among SAM. Many of the SAM patients see the need to carry on with prevention. (18)

Availability of the test*:*

Many patients don't get diagnosed. Two out of three HIV-infected in this population group are not aware of their HIV-status. Africans have themselves tested late: one out of five Africans got tested too late. (41)

A way should be found for implementation of evidence-based strategies to reduce the barriers to testing caused by stigmatization, discrimination, marginalization and criminalization. (42)
Amongst the migrants there is evidence of deprivation of Health Care Services. Access to primary care is limited by structural determinants such as immigration and Health Care Policy, which varies across Europe. For those migrants who have access to Primary Care and other Health Services, missed opportunities for HIV testing remain a barrier to earlier testing and

diagnosis for migrants in Europe. Clinicians should be aware of these potential structural barriers to HIV testing as well as low perception of HIV risk in migrant groups. (23)

Access to medication and other treatments:

For most African people, HIV diagnosis means death. Migrants come to European countries with high expectations about better Health Care and life, treatments availability, financial help and prolonged life expectancy, in particular those who were already diagnosed in their countries. Nevertheless, the incidence remains high for those who are born in Europe too. (16)

Belgium has a good Medical Care System and according to performance report, migrants are, in most cases, qualified as “vulnerable”. In 2013, it was estimated that the undocumented migrant population in Belgium represents between 85,000 and 160,000 persons, and all of them including migrants from the EU-28, but the estimation is very imprecise. This corresponds to 0.8%-1.4% of the general population in Belgium. In 2013, it could be estimated that between 10% (17,602/85,000) and 20% (17,602/160,000) of the undocumented migrants had at least one contact with the medical services during year 2013. (41, 43)

The assessment of patient-centeredness typically concerns the acknowledgment of patients’ needs, preferences, the quality of the provider-patient communication and the patients’ and carers’ involvement. (41). SAM HIV patients know about this and expect to access the care.

Good quality of care:

Some studies confirmed that many people indicated they received good quality health care, support and empathy from their treating HIV experts. Additionally, the main researcher observed that the participants did not show fear of discrimination during consultations with treating physicians. (44)

Knowledge about the disease, lifestyle and continuous education:

Lack of proper knowledge and awareness of HIV transmission is a problem among SAM with HIV. They admit having less knowledge about the disease with a desire to know more. (44) This applies also to the medical personal including Pharmacists. Participants of the study describe a Pharmacist getting tremors when he realized that the customer was HIV positive (44)

People living with HIV need information about the disease and its progress, details about how to chronically move on with daily life. It was revealed in Copenhagen that knowledge and resources regarding HIV testing and care in Europe and neighboring countries is crucial. (29)

Acceptance by the Health Care System:

Sub-Saharan HIV positive migrants know that in Europe there is accessible high-quality HIV care and treatment provided. (29)

Coming to Belgium, women know and expect that it is possible to have normal pregnancies. In one of the Antwerp studies a woman told: '*when I expressed my desire to have a child, my gynecologist sent me to the psychologist. I did not understand the reason, because I was not depressed and knew exactly what I was asking for. I know that in Belgium women with HIV get pregnant and have children. I would have been less worried if the doctor had given me some reasons why I could not have a child.* (44)

Excessive precautions are seen in different areas, although caregivers create barriers by showing too many precautions. In the study of Arrey, many participants perceived unnecessary precautions taken by health care providers, unfamiliar with HIV, as discriminatory. A participant vividly described the fact that she was always seen as the last patient, even if she was the first on the consultation list, because of a precautionary measure. (44)

Medical files need to be protected and secured against unlawful disclosure. Most HIV SAM patients complained about the label connoting their HIV status on the forms transiting from one service to another and felt stigmatized and discriminated that their HIV-positive status was disclosed to health care workers without their consent. (39, 44)

Right to freely go to a doctor and choose own Pharmacy:

Avoidance of, or delay in seeking Health Care occurs. In some studies, participants indicated that they avoided going to a GP or Pharmacy in their neighborhoods. In a few cases, participants reported changing clinics or GP's because of perceived maltreatment. They switched Pharmacy because of fear of being known or labeled. (44)

Prevention against depression and low self-esteem, stigma and discrimination:

According to some studies, low self-esteem, emotional stress and depression are major problems among SAM HIV patients. Several HIV patients have reported that they felt very low

and were often deeply sad, because of the way they were treated by the health care providers. Patients expressed that they never went to look for HIV, so no one should point finger on them. Some care workers talked in public while other patients were hearing the critics about people with HIV. (44)

3. Field study

3.1. Introduction

In the literature, some information was elicited about SAM and HIV in Europe and Belgium in particular. The field work aims to question Sub-Saharan seropositive migrants about their views in relation to the treatment and follow-up of their specific state of health by GP's. What do they experience and expect during their state of disease treatments and follow up?

3.2. Method

Study Design of this Master Thesis:

A descriptive qualitative study was conducted, using individual interviews. A major advantage was that the interviewer had the same culture origin as the patients, and also spoke the same languages. This made it easy to gain trust where patients can freely speak and be understood in their own dialects, which makes the interviews rich in information as well as emotions. The participants understood also that taking part in this study is part of ongoing education, and in this way they are taking part in educating others too. Their personal experiences and expectations are taken out of the depth taken interviews following a guidance of a script. (Attachment 1). Participants were individually interviewed after accepting to take part and signing up an informed consent. (Attachment 2)

Recruitment:

For this study, eight adult patients of Sub-Saharan African origin were recruited in Flanders through a patients' local group called MUUNGANO, where a meeting was hold. This took place after contacting a member of the group, responsible for the Ethical Commission at ITM. About 8 people attended.

Participants were informed about the study by summarizing the purpose of study. Those who were not present were contacted at home. Mostly from Antwerp and Brussels, more than 12 people accepted to participate. Most interviews were in Swahili, few in English and French.

Data collection: Data were collected by semi-structured interviews. The script was made beforehand with following main topics: experiences and expectations of SAM HIV patient about their care, their views about GP's being the main persons in the follow up. Participants could speak freely and there was a strong interaction with the interviewer. The interviewer constantly reflected on these interactions.

Data analysis: Data were analyzed in a thematic way. All interviews were audiotaped and written verbatim. The first step was to read the transcripts. Then, the coding process started with formulating descriptive codes. These codes were rearranged in higher codes and organized in a code book on paper in Microsoft ® Excel. (Attachment 3). Afterwards this code book was controlled by the promotor and used for analyzing the other interviews. In the last step the codes were organized in larger themes. Double check was done and approved by promotor. The chosen themes were copied in a table, ready for further use in writing.

Ethics committee and privacy: The data will be saved by the researcher until after the Master thesis and a possible publication. Afterwards, the data will be destroyed. Only the supervisor and the co-researcher (Leen Van der Jeugt) will have access to the research in the context of the analysis transcripts. The interviewees cannot be identified by the other members of the research team. The recordings and any backups will be destroyed at the end of the study. During the study, the data are only kept by the researcher. The details of these interviews are treated confidentially and encoded, in accordance with the law on privacy and professional secrecy.

The study was approved by an independent Medical Ethics Committee of the University Hospital Antwerp with the approval number 18/14/192. (Attachment 4) This was carried out in accordance with the guidelines for good clinical practice (ICH/GCP) and the Helsinki Declaration (2000), drawn up for the protection of people participating in scientific research.

3.3. Results

Demographic data:

Demographic table in combination with detailed information was made according to interview report. The experiences and expectations of Sub-Saharan HIV patients with primary care will be evaluated and explained according to the information received from the participants of the interview.

Table 1: Demographic Data

#	Country of origin	Age	Sex	Town of residency	Year of HIV Diagnosis	Reason for tests	Marital status	EDU	Partner disclosure	Partner HIV+ /HIV-	SM	Reasons for migration	Permanent GP?
1	Congo	50	M	Antwerp	2002	Student	Yes	University	Yes	Negative	No	HIV Diagnosis	No
2	Suriname	38	M	(…) Province of Antwerp	Belgium	Random test at GP	Girl-friend	High school	No	Negative (self-test)	No	Professional singer	Yes
3	Uganda	52	F	Antwerp	2001 in Belgium	Pre-operative test in Belgium	Yes	University	NA	NA	No	For therapy	Yes
4	Congo	48	M	Brussels	2014/in his country	Pre-operative test	Yes	High school	Not Yet	Don't know	No	Disease	Yes
5	Rwanda	71	F	Brussels	1980	Already sick	Yes+	Professional Nurse	No	Yes/ he was sick first	No	To get treatment	Yes
6	Rwanda	71	F	Brussels	1993 /2000	Husband died	Yes+	Nurse	No	Positive/ death	Yes	Treatments	Yes
7	Rwanda	37	M	Antwerp	2009	Sickness	No	University	NA	NA	No	Treatments	Yes
8	Tanzania	52	M	Antwerp	2001	ITM project	No	Primary Education	No	NA	No	Business	Yes

There were eight patients involved in the study, ranging from the age of 38 to 71 years. All the participants were free to talk and express their ideas. The main challenge was to find them as

they had activities, some had to work, and others had families to take care of. Most interviews took place in the weekends and sometimes late in the evening.

Results from interviews point of view

"HIV is equivalent to death": Many people of African origin are not aware of their HIV infection. The majority only discovered this when they already had AIDS and were very ill. When HIV is diagnosed late, precious time is lost for proper treatment and care. Taking an HIV test helps to improve and maintain health and knowing HIV status enables taking measures to prevent infecting others. Without knowing, one can transmit the virus. ITM has formulated an information brochure about the test, specifically for SAM people: There are only advantages, no matter what the result will be. If the test is negative, patients will have peace of mind and can take steps to stay negative. If the test is positive, they will get the right care straight away. Furthermore, in Belgium AIDS is not a fatal disease anymore. Thanks to effective medication, called 'antiretroviral therapy', HIV infection has become a chronic disease. Antiretroviral drugs are most effective when taken at an early stage of the infection. When one starts at a later stage, their effectiveness is reduced. Therefore, early detection allows beginning with the therapy at the right moment with the best effect. This medication is provided free of cost by law in Belgium.

Participants told that, when Africans are diagnosed with HIV in their own county, life stops and grieve starts. This is not the case anymore for SAM with HIV in Belgium, because the hope of life has become assured.

"When I knew I was positive, my head spinned, because in those days when you were HIV positive...., it was as thought you were going to die the next day. Tomorrow I am going to die so why pursue studies? I left my studies, because I would die tomorrow. He stresses out: *Why study? What would I do, study then die tomorrow?"* He continued expressing his sorrow; *"I can see death after a year or two."* (Participant 1:6)

"You have to understand that, the person coming from Africa, HIV remains and infection which is going to kill the person. (Participant 3:33)

Gratitude and a second gift of life: Participants are very grateful that in Belgium, they not only escape from death, but receive also treatment and financial support. In their countries of origin there was no possibility of getting medication, or they could not afford it due to economic

situation. *"Fortunately, I had a young brother who was living in Swiss, who started helping me. In 2002, there were already medications but they were very expensive, costing 100 dollars by month. My young brother was sending me 100 dollars every month and it is at that moment that I started looking for means to come to Europe, so that I can find care. Unfortunately, my wish did not succeed as quickly as expected. I got my Entry Visa in 2007 by the Embassy of Swiss*." (Participant 5:8)

Sharing their views about Primary Health Care in Belgium, almost all of them appreciated the quality of Health Care in Belgium. Participants were thankful for receiving their lives back. They appreciated the country which supported them till now. She exclaimed: *"And I call Belgium the country of no language, because I am from English speaking country. There would be no any reason why I would choose to live in Belgium, but I am so glad that, again it is a Belgium that gave me a second gift of life" (*Participant 3:19-20).

Most participants didn't know if they will live again, but here they are in the country where the Health Care can support them to get a normal life. The joy was expressed in the conversation of almost all the participants.

Primary Health Care in Belgium is available for everyone: Sharing their views about the Health Care System, all of them had access to a doctor and received medication. In the group interviewed, one of the participants was still homeless. She had no legal permission to live in Belgium, but had access to HIV consultations and treatments and also, she had access to a GP. She explained: *During that year, (2011), there started a new rule stopping granting residence permit to people with social cases like me, and it is in that way that I lost the legal residence in Belgium. So, this is my history. So, I have been treated in Antwerp. I apologized requesting them to keep giving me medicines, but I was not given them. They only kept sending me to social assistants at OCMW. In OCMW, they could not allow money every month to a person that has been asked to go back home. At a given moment, I got by chance a small place in Brussels reserved to Homeless people and from that year until now, I am getting care under a homeless status.* (Participant 5:9).

All participants received Health Care in different stages. Some people delayed going for the test, because of lack of registration in the Belgian system, but they later received advice through OCMW. People of African origin and other continents who are still not enrolled in the Belgian system, both in Flanders and Wallonia, could receive medical help through ITM Antwerp. This Institution was free to receive SAM people for the tests, even those who had no papers (or migrants with no registration). Under Belgian law, free antiretroviral therapy is offered to

everyone living in Belgium. Even people without a legal residence permit can get medication through the OCMW/CPAS: *"I was very ill and had no residential permit, when I was found HIV positive. A public health nurse came to talk to me and I was started immediately with medication regardless of my status"* (Participant 8:2)

Treatment and follow-up

Adherence to treatment: Coming in a country full of discipline with no discipline is a challenge. In the beginning SAM HIV people were lacking knowledge about the disease and its progress. Even now interviewees admit that they lacked discipline to follow treatments' regimes, but due to fear of severity of the disease and receiving knowledge about importance of consistency in taking medication, they succeeded. It required training. Many admitted not having heard about adherence before they came to Belgium. They have developed discipline with years of follow up.

"But to tell you the truth with HIV, you need consistency. Now in Uganda we are good with HIV, but the medication is not there all the times so you will not be able to be consistent." (Participant 3-:6).

Those who already received good information developed an European standard of discipline in taking their medication constantly and at the same hour of the day. Participants expressed their experiences while being on follow up of their treatments for several years in Belgium. They had two places where they had to go: to a Specialist at an Aids Reference Centre and at a GP setting, both for different tasks. They go on fixed times at ARC, but they have access to a GP all the time, despite of some challenges which we can see later.

ARC specialist task division: According to participants' experiences and explanations, everyone went to see a specialist once or twice a year for specific reasons. That is **to check the state of the disease and development of the symptoms** during the period of treatments.

The patients also received a **laboratory test** and the specialist told them the state of viral load and CD4 counts. **Advice** is given to them on how they should continue with their lives. Their sexual life is also received and advised for those who are open to talk about it. **A letter is sent to a GP with accordance of a participant**, and almost all of them had a GP. A participant expressed: *"The treatment I usually do after six months. But now they have told me to come after one year".* (Participant 1:23) During the day of consultation at ARC some participants get **psychological support.** They visited at the same time a **psychologist and a public health**

nurse. *"You don't know if you are going to live, so, psychologically, when they tell you to take medicines and take it all the times, you need that psychological support which you don't have."* (Participant (1:27).

The main challenges for the ARC specialist: The participants observed that there is a change in their **consultation time**. In the past years they had enough time to spend with their specialist, but that is no longer the case. Specialists have become selective to do only one part of their concern, but for all other problems, patients have to go GP for follow up. The time has become shorter during consultation according to some of the participants. One said: *"We used that time to have enough time with the doctor.* (Participant 3:28)" She continues to explain with a lot of emotions: *"Now, you have only 15 minutes. These 15 minutes are finished before you remove your jacket in Belgium. The 15 minutes are over, your viral load is good, the virus is undetectable. Do you still have another question? Good bye."* (Participant 3:58) Some of the participants seemed to have enough time with their specialist. This may depend on whom and on the compatibility between the two, but in general the consultation time has become shorter compared to years ago when the disease started. It can be expressed by the increase of number of patients and by ARC specialists having more patients.

Hidden problems are not easily discovered and solved

Missed medication: Some participants have given a signal of attention that SAM HIV patients need enough attention of the Medical Doctor at ARC to express all their hidden things, but unfortunately for some of them this aspect was missing. Patients are suffering from other problems than only viral load and CD4 count. With laughter and a lot of emphasis a lady explained: *"(Laughing together): You want to tell the doctor that you went out with the boyfriend and he threw you out!! Laughing hahahaha (really fun); You want to tell him that your medicines were hidden in the cups, because you removed the cover and put in the cups because of stigma and discrimination, you put in the vitamin Tins, and the boyfriend throw them away, now you don't have medication anymore. Before you tell the doctor he has already sent you out of consultation room, so you stay few weeks without medication. Doctors are not discovering this so now."* (Participant 3:58-59)

Drugs adverse reaction and interaction with other medication are not always discovered: In the course of follow up, it is shown by some participants that when they got a drug reaction, it was not easy for the specialist to notice it immediately. They were easily noticed by GP's. For

someone who didn't have a GP, it was very difficult to go directly to the Third Line without any referral letter.

Sexual and relational matters are not completely handled: There are some participants who wish to get married and have children, but they still don't know how to go about it. Other participants have girlfriends who still don't know anything about their HIV status. This is dangerous. Some of them are concerned about what to do when the girlfriend becomes pregnant. They are hiding their status and are full of fear. ARC must foresee this information, but it seems the focus is on individuals with HIV, not on the persons around them. Probably they assume that these people already know, but from this study, majority of participants had still unanswered questions of which they didn't know to whom they should address to. Some participants explained that they can freely have sex without any protection, when asked about their sexual behavior. He replied: "*My sexuality is open. I can do it. You don't have any difficulties, any psychological problems."* he replies, *"no, that's all, that's all, because the doctor of the Tropical Institute explained to me. He learned me how I can do that, he told me when I can begin. He told me that sometimes it can be more than 6 months. He let me wait till December, once he looks about things in my blood information, he told me you can begin sex without a problem*" (CD4 and viral load) (Participant 2:16).

The participant has received information that nowadays, condom is not important, but medication is. He continued: *"I don't have to use condom"* really? *"Yes, zero hahaha, yeah. Yeah, good news because you tell me that's when you take your medication on the really time, because I have a time that I have to take it when I see the clock boom. It is not necessary to use condom because my girlfriend the doctor asked me if she don't know. I said no. But she is checking on herself (testing for HIV), yeah she was checking two weeks ago, she was checking every time and it is negative."* (Participant 2:17). There was a controversy between his GP and his specialist since he went to his GP. He is advised to protect himself and to let the girlfriend know that he is positive.

Worries about unborn children: These are issues that have to be well addressed and taken care of, but unfortunately, if the patient will see his doctor once or twice a year, there may be no room to address this question.

Is treatment and the follow up of SAM HIV-patients a GP task?

The responsibilities of a GP are huge: From the interviews this is clearly observed. Patients go to the ARC for their viral load control and medication prescription once or twice a year. The rest of the time they are alone and have to be followed up by their GP in case they need help. Many of the participants have developed a good relationship with their GP. According to the observations, almost all participants had a GP, except one. This makes a GP a very important person in the lives of SAM HIV patients, despite of different challenges that are to be discussed later in this study. Literally it is seen that the HIV patients are taken care of by specialist at ARC but in reality, their lives and daily problems are in the hands of a GP directly and indirectly. This brings us to the point that a GP will almost always be daily confronted with HIV.

"Having a house doctor is good. I had a house doctor personally and the children. The whole family went there. It is good, because you can see him easily without waiting for a number of days to see him. But when you go to the Institute, you first have to take an appointment" (Participant 1:29)

GP's can do all what ARC specialists do and even more: One of the participants said: "*What can I say is that, people who have AIDS and who have different issues, they need to have a house doctor. You can call a house doctor to visit you at home, another (ITM) doctor cannot come home, and you have to go to him. It is important to have a house doctor. You can even meet him on the street and tell him things are not good, he will tell you: find time to come and see me."* (Participant 1:39).

GP's are available all the times: In case of any problem participants managed to make appointments with their GP's all the time. One participant explained that all what can be done with the specialist, can easily be done with a GP. They can perform blood tests and evaluate their results. GP's are able to see the patients during the year to discuss not yet discussed matters and to solve unsolved problems. Participants had many questions but didn't know whom to ask. Being asked if she could go to her GP when a specialist is no longer available, she replied: *"I think that, it can still go well even in that case. We go to specialists because they are made available for us but even the family doctor is able to do the same. The specialists do not do something special for me. For instance, when they prescribe tests to me, even the family doctor can do it and he is able to read and understand the results.* (Participant 6:17-18).

GP's treat their patients as a whole*:* We have to realize that HIV is not the only situation of the patients. Some patients think that it is possible to go to the ARC for HIV and to the GP for other medical conditions. They often forget that the body is a system that cannot physiologically be divided into HIV problems and non-HIV problems. Outside ARC many interviewees declare the need to go to GP for all other problems they could not share with the specialist. At the same

time GP needs to communicate with the specialist for all what the patient is receiving. *"When I go to the Tropical Institute I cover myself with winter coat. Who will know that there is one woman from inside my country, the winter jacket, so that is it.* She continues to elaborate: *"Ah! The doctor requested, "Should I send the information to your house doctor?" I said No! For what? The house doctor is going to treat my headache, he is going to treat my child when he falls down. But I am coming to the specialist. I am not going anywhere else. Yes, because of that stigma one person knows it is one person, you are not telling my GP. My follow up is at the Tropical Institute. And I with time came to trust my GP again through again the numerous operations on my foot here in Belgium. The GP had to come and check me at home."* (Participant 3:33-35)

The participants declared the moments of ups and downs during which they could go for consultation at the GP's practice to receive more help and direction. The ARC had a psychologist for them, but this service was not always realistic, when someone was in urgent need. For some who develop suicidal thoughts, the closest person is a GP.

HIV patients have complications during treatment: Participants had other problems which needed solutions. Some underwent operation and needed follow up. *"My house doctor had to come and check on me at home after an operation on my foot and the rest he could pass on whatever I said to my doctor, I think you better give my information to my GP" (*Participant 3:38)

GP's are in a position for giving continuous education to their people: Knowledge about the disease, lifestyle changes and future plans can be guaranteed several times in a year by GP consultations. Some participants benefit individual teachings rather than groups teaching. This is due to fear of disclosure, stigma and discrimination. Participants have great plans to support education and spread information in Flanders. One explained: "*No it best I want: to learn more about my situation, but I love to be in private I love the private"* (Participant 2:14)

Conflict situations at ARC: It was sorted out during interviews, that some patients developed misunderstandings between them and the ARC specialist. In this case it became difficult to change or find a new doctor. In some conditions a specialist used his power to suppress the patient by refusing to change the drugs after side effects. He explained: *"When I started the treatment, I got bigger problems; my body did not tolerate the medicine. The reaction to medication was enormous; I could have scratched myself with a knife. I went to see my medical doctor at the Institute. I do not have another doctor. I went to the doctor and told him, Sir, since I started this medication, it is not*

working, I scratch myself a lot, and can you do something? The doctor refused to change my medication." (Participant 1:17-18).

Challenges for the GP

Fear of disclosure/stigma: Many of the SAM HIV patients feared to be known by others and also by the local people. But they also feared other doctors and medical workers knowing their HIV status: She exclaimed: "*So once you have one specialist doctor who has known, you will wish not to have any other doctor, even when you go to an Institute of Tropical Medicine where there are all professionals. You don't even want to meet another doctor. When they say the doctor is going on leave, you say, i will see him when he comes back; they will say "no, no, no, you need to see another doctor. You will say: no, I will rather die, i will have to wait, because you think the information is going to go away."* (Participant 3:33) GP's are community persons who address many matters and meet many people at their surroundings. The interviewees fear that if they go to a GP closer to them, information can leak and people around them may know. One expressed: *"We are coming from another culture, professional culture where even the doctor will decide to have a drink and say: by the way today I was treating the daughter of Mr. X, the other neighbor of ours. So, you would keep thinking that here (in Belgium) it will be the same*." (Participant 3:34). She continued: "*I know I am here 17 years, I have being passing around talking to everybody and showing my face. That time we would pray that it is winter and everyone is covering his face with his jacket, so no person in the clinic may know you."* (Participant 3:35)

Lack of trust from SAM HIV patients' side: Some patients have lost their trust in GP's, since they are not sure that the doctors can keep their secret. They might talk to other persons beyond their job. This makes them hesitate to go to a GP. Trust will only be developed after a long time of contact. *"So I am in safe hands, because what I have learned, which also I think we are talking about house doctors having an issue, but I think I talked to you about also our culture, our background. We also don't know, are they to be trusted? You think the doctor who knows your problem today is the only doctor. We need also may be some information which says that when the doctor is a doctor"* (Participant 3:52).

Lack of HIV Knowledge/Training for GP's: GP's cannot escape HIV problem since it is well spread and becoming chronic. SAM patients are taken as a reference group, but in the community there are also people from other nationalities who are HIV positive and need help and support. Participants explained situations where a GP gave them medication which should

not be combined with HIV medication, because GP's are not receiving updated knowledge about HIV and its treatments**.** *"We need something to equip the GP's when they have been noticed by the specialist there is still remains a being with all other infections that may not let us say that often are not related to each other."* (Participant 3:68). When enquired about how a GP should be, one answered: "*He has to have knowledge to treat different people. They need to have a variety of skills also. I would advise them (GP's) to know what is going on in life. When he is called a doctor he also must know about this disease (HIV) and be able to work with people who are suffering from this kind of disease. So, a person who wants to go to them he can confidently go.* (Participant 1:30)

Overreaction by some GP's: This is felt by participants as discrimination and partly understood as lack of knowledge. They observed GP's washing their hands several times after talking without clinical examination. GP's can do this subconsciously, but patients notice it. One said: "*Eh!* (*Special Swahili surprise sound) Because some people, when you go to visit them, they tell you that you are HIV positive. When he goes to the bathroom, he washes thoroughly. I do not know which type of soap he uses (with a lot of laughing and expression).* He continues: *"I can understand you well (he is still laughing). He thinks that you (hesitates), people are very stupid. It is not a good thing."* (Participant 1:33)

Some GP's escaped their responsibilities and pushed people to ARC: Some of the participants explained that when they went to their GP's, they were sent back even when they have non-HIV related issues. This is expressed as being chased away, rejected, sent back to the owner of their disease, which is then considered to be ARC. She said *"For sure some GP's tell people: you are HIV, go to your doctor at the tropical institute***",** he added. When this trust is established then they can have more confidence and continue to go to their GP**.**

Financial problems: Some participants revealed that the reason of not going or having a GP, is that every time you make an appointment, you have to pay. They prefer not to go to a GP and rather tell all their problems to their specialist. He described: *"I would need a GP, not that I would need to pay him monthly, but rather when you are sick you go to see your doctor, you need to pay the consultation, and it is not for free."* (Participant 1:25)

Not feeling sick due to improvement of one's health status: Some patients think that they are doing very well and they don't see any reason why they should find or go to a GP. When one of the participants was asked if he has a GP, he replied: *"Hahahaha, I do need a house doctor*

but at present it is not important, I don't feel sick and also I am trying to arrange things at home." (Participant 1:24)

Violation of the privacy

Suffering of different traumas during the state of migrations process: One participant told how she was exposed in front of people in the state house by personnel who shouted that she should bring a letter which says that she is HIV positive.

Medical Files: Almost all participants, except one, refused to share their medical files publicly, even in the medical set for different reasons. When going for other type of treatments within a medical setting, the file is labeled in a special way of which all other people know that the participants was HIV positive. This was not necessary. One explained: *"I have found it very demeaning and hurtful in this days and age you go for Physio and your file either colored to show that your HIV, and then it has a mark on top of it: you're going for Physio!! it is written 'HIV' with red or pink or yellow, it has to be bright. What has my Physio got to do with the fact that I have broken leg or have a wound? They need to tell that person "don't touch that blood is going to kill you. If they want, it is your professional thing, you need to talk to doctors and others and say she is positive, but you don't need to put my file here and give it a name and give it to physician, to kinesist* (Physiotherapist) (Participant 3:69*)*

Pharmacy and Medication: Most participants get their medication in the same pharmacy all years long. The pharmacies chosen are known and deliver the medication discretely without mentioning the names of the medication ordered in public. One of the participants was afraid to ask her medication in public in a pharmacy, but she used wisdom to cover her HIV status**.**
When another person knows that they have HIV, there will be for sure discrimination, so the best way is to try and hide all the information in one roof and that is ARC. Some people have to hide, even when going for medication in ARC: *"When I go to the Pharmacy, all the people know me, so they keep everything. Every time I go, I see another pharmacist. I ask 3 or 4 packets of medication and when I go back by the time I finish the 4 packets, there will be another who does not know me. In this way I hide myself."* (Participant 2:21. Elaborated text, due to participant's language problems)

Concerns for the future about aging with HIV

A participant was concerned with her age. She has seen a lot of rejection between the Medics and Paramedics during her treatments in Belgium. She wondered what would happen when she

gets older. She asked: *"And I want about beyond, when we grow old and we are going to go to the rust house, I wonder what is going to happen? So now, that is why I tell you again training refresher courses, because this care keepers and the cleaners and whatever other time they were just cleaning and passing by, but Old Age and HIV? She gives a sound of sorrow." (*Participant 3:76)

4. Discussion

This study has qualitatively brought us to understand the position of GP's in the life of SAM HIV patients. Different issues have come to light about HIV Care in Belgium.

GP's are central figures in the diagnosis and continuous care. (45) Long before HIV was known, GP's came in contact with sick persons who were still not diagnosed. It is acknowledged that GP's contribute greatly to early case finding. (46) According to the description of some writers, HIV is not a new disease for GP's. They were the first to consult the patients in the 1980's, when patients had symptoms of weight loss, and extreme tiredness.(18) With aging and availability of treatments, it has become a chronic disease. (8) In this case GP's are important persons. The follow-up of HIV patients cannot be a task for a specialist alone. There are still new cases which will need tests where GP's are the closest persons to perform them. Everyone cannot go to an ARC for screening. There is a need to recommend the expansion of HIV testing beyond the Antenatal and Sexual Health Clinic settings and to advocate routines to offer HIV tests to all adults registering in General Practice settings. (2)

Flemish GP's involved in promotion of HIV tests in 2012, proved that in Primary Health Care GP's were the perfect people to support provider initiated HIV testing and counseling, in order to decrease spread among SAM people.(42) Figuero describes the importance of GP's in this way. The terminal AIDS patients are very immune-deficient and need palliative care like other terminal patients. Another challenge is prevention and control of HIV infection among the immigrant community. A 'Family Physician' must investigate risk practices, inform, prevent new cases and monitor the evolution, support and comfort of the infected people. GP's remain central persons in this matter. (2)

Fragmented care is the expression we can use when HIV patients, according to interview results, are centralized at an ARC, despite of good continuity in care among SAM with HIV in

Belgium. (30) There still is something that separates the health care into two parts. Each one of the participants had a specialist whom he/she could meet once or twice a year. How long though will this be possible in the future? New cases cannot all be diagnosed at ARC. Especially for SAM people who acquire HIV in Belgium, GP's are the ones who will discover this disease during their observations, tests and STI screenings. How do we unite or separate the fragments in terms of tasks between ARC and GP's? Can a human psychological system be divided? We need a holistic way of approach on both sides.

Elderly homes for persons with HIV in Belgium: HIV persons can now get older with HIV, as studies confirm, providing an historical account of HIV activism, clinical treatment, and pharmaceutical research in the 80's that transformed the disease from an acute and consistently fatal condition to one that promised to be manageable over the long term through drug therapy. (47) Though some participants were in their seventies with good health, they remained worried about their future. Aging with HIV is a great issue in the minds of these patients. Will they be sent to ARC's with wheel chairs and ambulances? Will this be affordable? Soon they might be widespread into elderly homes. Participants feared to be discriminated, isolated and even mistreated in the future there. Will professionals of elderly homes be prepared to deal with HIV? Who is responsible for this? As people with HIV get older, just like other people, they will more likely develop conditions like diabetes, heart disease, arthritis, kidney disease and hypertension. GP's regularly attend elderly homes. Those conditions are best managed by Primary Health Care doctors in elderly homes. (48, 49)

Education /Training for GP's and other medical professionals are important: The ARC's produce courses to be attended, but are they conducive for GP's? The way has to be found where the GP's, who really want to be involved in HIV care, can receive training. Probably the interested GP's may receive training as part of their accreditation. Or should the training be generalized, so that every Belgian GP will know how to treat and go about HIV? In this case, ICHO, Domus Medica, FOD and all other related organizations should work together to raise the standard of GP's and other medical workers. On patients' side, interviewees reported that the past years more formation and congresses about HIV were offered, but not anymore, although HIV is still a problem for the newly diagnosed people and those who are not yet diagnosed. The study of Lazarus addressing the conference in 2012, discussed in details the barriers of testing and reasons of late presentation. One of the recommendations was to increase interaction, to

raise awareness among clinicians within different specialties and implement indicator disease-guided testing. (33)

The participants manifested doubts and a lack of knowledge: There is little understanding about disclosure. Instead of taking this as negative, there must be a way where it can be used to help and protect others. After SAM HIV patients were informed that they had undetectable viral status and high CD4 counts, many have sexual partners and never told them they were positive and even having sex without condoms. The treatment success had made some of the patients reluctant in protecting themselves. This information is not sufficient to have freedom for different sexual partners. Some didn't know either whom they should ask when they want to have children. It can be very traumatizing for a woman to know only after her baby is born, that the father is HIV positive. Such kind of attitudes was expressed by some participants. Disclosure is still a big problem among SAM HIV Patient. (19, 21, 34, 39)

ARC and GP working together: Often there is a good communication between both, but not enough. GP's are following up different problems of their patients, but do not enough know the specific information of HIV medication. The chance to prescribe some medication which can influence the HIV treatments is great. The participants revealed, receiving Proton Pump Inhibitors by a GP and deterioration of CD counts being noticed by a specialist. Other challenges were also found when a GP had struggled to give education to her HIV patient about protective sex, few months later the patients declared that the specialist had allowed him to have free sex without condom. So he again took a girlfriend without informing her that he was HIV positive. This can be a serious problem. It seems that some patients feel they are healed completely. Working together between the GP's and ARC specialists should to be more detailed.

Discrimination and stigma remains a big problem in the medical setting and publicly. Some interviewees were mistreated, but had nowhere to go and report it. There has to be a unit where patients can complain and be helped in case of any unacceptable action towards them. And if they have to report, action should be taken toward the medical personnel involved. Some studies have measured the stigma index, but this has to go with actions. (43, 44)

Future plans: The HIV patients want to participate in preventive measures by providing free education in Flanders. They want to support others who have similar problems. He said:

"We shall visit Turnhout, we shall visit Gent, we shall visit the whole of Flanders! We meet people and inform them that you can live, when you have problems like these. Send them to us, we shall inform him when there is such a problem. We are still alive twenty years with the treatment. (Participant 1:35)

Medical Schools of Belgium have to give HIV lessons as compulsory and GP's can receive accreditation training and receive a certificate to work with HIV patients. A Centralized Data System has to be formulated to avoid losing data of some people who are receiving treatments by GP's. Belgium as an organized country can make this possible. GP's should be stimulated to take part by paying them extra money which they deserve, since all the dangerous or undiagnosed cases mostly go to GP's first before going to specialist. Disclosure has to be stimulated; contaminating someone else intentionally or consciously can be penalized. Hiding status and getting married to discover the truth at maternity bed is not ethical.

5. Challenges and Strengths of this study

Several limitations were encountered during the course of this qualitative semi structured interview study. After passing all the requirements needed with the Ethical Committee of the University of Antwerp, contact was taken with different professionals who were in touch with Sub-Saharan African HIV patients or local groups of them. It was not easy to locate such HIV patients. Getting permission to meet some groups and accepting to participate in the individual interviews took time as well. Everyone being busy with daily life, having families and other activities, it was hard to fix individual meetings with those who volunteered to be interviewed. Some appointments took place after 10 p.m. The interviewees lived far away from each other and it was difficult to find suitable places to talk quietly and to record the interviews without interferences. The lack of the needed language knowledge of the interviewees was a problem. Some of them used dialects and symbolic language, known only in their culture, which needed to be understood and elaborated by the interviewer. The interviewer had to interact with each one in his/her own common language. Afterwards much time was needed to transfer the information from spoken audios into a written document having one scientific language. All participants were concerned about the security of their names and other information to be revealed. They also appeared to have some different experiences, so they cannot be generalized.

It is a merit that the methods used with the interviewees facilitated expressing experiences with openness and from the bottom of their heart. The interviewer coming from a similar culture,

made it easier to express emotions. Participants often ended up to speak with enthusiasm. The fact of most participants belonging to a local group that had met regularly, helped to express what was already dealt with. All of them had also been in contact with a GP and they managed to share what they felt as going right and wrong. It is a merit that we got to know some needs of Sub-Saharan HIV patients for the future of their Health Care. The results from this interview study may help to shape and design the follow up of SAM HIV patients living in Belgium. It may also help to awaken the Primary Health Care to plan ways of equipping GP's with knowledge and making them aware of an existing and up to date HIV Care with appropriate follow up of such patients in Belgium.

6. Conclusion

- This Master thesis has made clear that the structure of follow up of SAM HIV patients in Belgium is the same in the whole country: The ARC's are the main places where patients go for their medication, laboratory tests and evaluation of the progress of their disease.

- Good treatment schedules and adherence to therapy have led to better health outcome, hence chronicity of the disease and long life expectancy. So the number of HIV patients has increased. The interviews confirmed that ARC specialist have got less time per patient than years before. This probably means the ARC's will not manage anymore to follow up all the HIV patients in totality and can no longer well function alone.

- The more people age with HIV, the more they become stable, hence appearance of other chronic diseases like hypertension, diabetes, heart diseases and daily injuries. They need parallel treatment and follow up. GP's are the best permanent persons who are always confronted with these patients in emergencies and chronic long term diseases.

- GP's can no way escape the task of caring HIV patients in their daily practice. This happens knowingly or unknowingly. For patients who are still not diagnosed, usually GP's are persons who have a good chance to ask for the test during general check-ups.

- Good communication between GP's and ARC specialists is mandatory to ensure complete care and good collaboration between First and Second Line Health Care.

- The shifting of all the tasks of ARC's specialist to GP's is not possible at this moment. Shared care with good communication can bring the best results in the follow-up. More studies are needed about how to equip GP's and keeping medical information's such as statistics.

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Attachments

1 Protocol and Script

2 Informed Consent

3 Code Book

4 Final Positive Advice of Ethical Commission

5 Patients Information

Protocol and Script

PROTOCOL

Topic: Opvolging van HIV in de huisartspraktijk: Patiëntenperspectief van de Sub-Saharaanse migranten (SAM)

Naam student: Mallya Flotea
Promotor: Prof. Dr. L. Peremans
Co-promotor: Kathleen Verheyen

1. Onderzoeksthema

Afrika is een continent dat zwaar getroffen is door HIV. De ergste epidemie op Sub-Sahara bevindt zich in Oost- en Zuid-Afrika. De snelle toename in Sub-Sahara kan verklaard worden door een complex samenspel van seksueel gedrag dat beïnvloed wordt door de culturele en socio-economische context. Ook in België en in Europa vergroot de problematiek door de populatie-toename van migranten uit Sub-Sahara en mannen die seks hebben met mannen. In Europa heeft België een van de beste concrete HIV-behandelingsplannen. De meeste patiënten worden er behandeld in de tweede lijn, namelijk in Aids Referentiecentra zoals het ITG. De belangrijkste therapeuten in de eerste lijn zijn huisartsen. Uit een vroegere masterthesis weten we echter dat deze groep patiënten vaak de huisarts niet inlicht over zijn/haar ziekte. Het doel van deze masterproef is om Sub-Saharaanse seropositieve migranten te bevragen over hun opvattingen i.v.m. de behandeling en opvolging van hun specifieke gezondheidstoestand door huisartsen

2. Onderzoeksdoel

In een voorgaande masterthesis werd de kennis en attitude van huisartsen bij de HIV-zorg onder de loep genomen. Momenteel is er een onderzoek lopende naar het patiëntenperspectief van seropositieve homoseksuelen. Samen met de Sub-Saharaans-Afrikaanse Migranten (SAM) vormen deze de grootste groep seropositieve patiënten in België. Het patiëntenperspectief van de SAM ontbreekt nog.

3. Onderzoeksvraag

3.1. Onderzoeksobject

HIV-zorg in de eerste lijn

3.2. Onderzoeksdomein

Zorg voor HIV-positieve patiënten door de huisarts. Patiënten van Sub-Saharaans-Afrikaanse origine, ouder dan 18 jaar, met een stabiele ziekte en niet in de opstartfase van de behandeling.

Taal gebruik: Engels, Frans, Nederlands, en Swahili.

3.3. Onderzoeksvraag

Welke verwachtingen hebben Sub-Saharaanse HIV-patiënten rond de hulpverlening in de eerste lijn?, Zijn de behandeling en begeleiding van HIV-positieve migranten van Sub-Saharaanse afkomst in België geschikte taken voor huisartsen?

4. Onderzoeksdesign

4.1. Literatuuronderzoek

Hoe verloopt de hulpverlening bij de Sub-Saharaanse populatie in het westen? Welke verwachtingen hebben ze rond de hulpverlening?

MESH TERMEN: "HIV AND SUB SAHARA AFRICA", " HIV IN EAST AND SOUTH AFRICA", "HIV IN UGANDA" "HIV AND SUB SAHARA MIGRANTS IN EUROPE", "HIV AND SUB SAHARA MIGRANTS IN BELGIUM"

4.2. Veldonderzoek

Kwalitatief descriptief onderzoek met semi-gestructureerde interviews, met focus op 10 landen van Sub-Sahara uitkiezen en hun migranten met HIV die in België wonen, contacteren. Patiënten worden bevragen over de begeleiding en behandeling van hun ziekte door huisartsen. Wat denken ze hierover? - Is dit gemakkelijker of beter dan in een gespecialiseerd centrum? - Wat zijn hun ervaringen hiermee? - Wat zijn hun suggesties?

Patiënten zullen gerekruteerd langs ARC of wel met gebruiken van etnische organisaties die samenwerken met ARC, mond tot mond reclame, organiseren van evenementen waar migranten met HIV samen zullen komen. Maximum 15 patiënten als het mogelijk is.

Noot: Dit onderzoek is een duo-thesis in samenwerking met Van Der Jeught Leen waarbij het literatuuronderzoek en het veldonderzoek afzonderlijk uitgevoerd wordt doch de resultaten samengelegd zullen *worden.*

Een aantal demografische gegevens wordt voor aanvang van het gesprek verzameld door middel van een korte vragenlijst (cfr. bijlage).

Het script is in bijlage bijgevoegd. Na het eerste interview gebeurt er een eerste analyse en wordt het draaiboek/topiclijst aangepast indien nodig

Datacollectie en analyse:

Alle gesprekken worden op audio recorder opgenomen en letterlijk uitgeschreven, waarna verschillende onderwerpen worden gecodeerd. Via thematische analyse met behulp van de software 'Nvivo' worden deze gegevens kwalitatief verwerkt.

5. Ethisch comité en privacy

De opnames en eventuele back up's worden na afloop van de studie vernietigd. Tijdens de studie worden de gegevens enkel bijgehouden door de onderzoeker zelf.

De gegevens van deze interviews worden vertrouwelijk behandeld en gecodeerd verwerkt, in overeenstemming met de wet op de persoonlijke levenssfeer en het beroepsgeheim.

De studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek van het Universitair Ziekenhuis Antwerpen. Deze zal worden uitgevoerd volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki (2000), opgesteld ter bescherming van mensen deelnemend aan wetenschappelijk onderzoek.

6. Planning

Literatuuronderzoek (maart 2018-november 2018)
Contacteren deelnemende centra (maart-april 2018)
Uitnodigingsbrieven meegeven (april-juni 2018) (van zodra goedkeuring ethisch comité)
Interviews (juli-augustus 2018)
Dataverwerking (september-november 2018)
Uitschrijven onderzoek (november 2018-februari 2019)

HIV zorg in de eerste lijn: patiënten perspectief van Sub-Saharaanse Afrikaanse Migranten

7. Script gesprekken

7.1. Introductie

Protocol: *HIV-zorg in de eerste lijn: perspectief van de patiënt* Masterproef huisartsgeneeskunde - *Versie 1 - datum aanvraag: x* Van der Jeugt Leen

> Verwelkoming door Mallya Flotea: kort voorstellen en inleiden masterproef, bedanken voor medewerking
>
> Welkom. Ik ben Mallya Flotea. Voor mijn masterproef doe ik onderzoek naar de begeleiding van patiënten met HIV van Sub-Saharaans-Afrikaanse origine. Het doel van dit onderzoek is een zicht te krijgen over hoe patiënten de huidige begeleiding van HIV bele-

ven en wat hun visie is rond gedeelde HIV-zorg tussen de huisarts en de specialist. Het interview zal ongeveer 50 minuten duren. U mag ten allen tijde aangeven wanneer u het gesprek wenst stop te zetten.

Het gesprek zal opgenomen worden, om het later te kunnen uittypen en analyseren. Nadien wordt de opname vernietigd. Naam en persoonlijke gegevens worden vertrouwelijk behandeld. Ze worden nooit expliciet vermeld in het onderzoek. De gegevens worden enkel gebruikt voor wetenschappelijk onderzoek en worden behandeld met respect voor de privacy.

Tijdens het interview zijn er geen juiste- of foute antwoorden. Het doel is dat u uw eigen idee deelt. Voor de start van het interview zou ik willen vragen een korte vragenlijst met persoonsgegevens in te vullen (demografische vragenlijst, cfr. bijlage). Deze zullen behandeld worden via codering en met respect voor de privacy. Heeft u nog vragen over het onderzoek?

Vooraleer we beginnen vullen we, indien u akkoord gaat deel te nemen aan het interview, het toestemmingsformulier in tweevoud in. Eén exemplaar is voor u, het andere hou ik bij. (invullen formulier, invullen demografische gegevens)

Zou ik u vriendelijk mogen vragen uw GSM af te zetten tijdens het interview?

Vanaf nu zal ik het opnameapparaatje aanzetten. Heeft u nog vragen?

Ik ga u de vraag ‘Bent u akkoord om deel te nemen aan deze studie?’ stellen eens de geluidsopname begint. Indien u akkoord bent, zegt u ‘ja’. Indien u niet akkoord bent zegt u ‘nee’. Nadien gaat het interview van start.

7.2. Vragen

a) Openingsvragen (situatieschets eerste confrontatie met seropositiviteit)

Topic 1: De context van de patiënt

Wat is uw leeftijd?

Hoe lang verblijft u in België?

Hoe is uw leefsituatie? (alleenstaande, familie)

Topic 2: Het ziekteverloop

De confrontatie met de diagnose

- Wanneer heeft u vernomen dat u seropositief bent?
- Wat bracht dit bij u teweeg?
- Wie heeft bij u de diagnose gesteld?
- Wie heeft u de diagnose meegedeeld?
    - Indien het een huisarts was, is dit dan uw eigen huisarts?
        - Zo ja
            - Had u liever gehad dat de diagnose door iemand anders medegedeeld werd?
        - Zo nee
            - Is uw eigen huisarts op de hoogte van de diagnose?
                - Zo ja, wat betekent dit voor u?
                - Zo nee, wat maakt dat de eigen huisarts niet op de hoogte is?
- Hoe verliep de mededeling van de diagnose?
    - Had u het gevoel dat de mededelend arts hierover op een vlotte manier kon communiceren?
        - Werd de diagnose op een empathische wijze gebracht?
    - Gaat u nog naar deze arts?
            - Zo ja, wat betekende deze mededeling voor de volgende contacten met die arts?
            - Zo nee, wat is de reden dat u niet meer bij deze arts gaat?
- Wie is er verder op de hoogte van de diagnose?
- Hoe gebeurde de verwijzing naar het Aidsreferentie centrum? (via brief, huisarts contacteerde specialist,...)

Behandeling en opvolging

- Wanneer en waar is de behandeling opgestart?
- Hoe verliep dit?
    - Was er samenwerking met de huisarts?
- Waar krijgt u uw medicatie?

Focus op het Aidsreferentie Centrum

- Hoe bent u hier terecht gekomen? *(indien het niet door oorspronkelijke verwijzing was)*
- Hoe lang bent u onderweg naar het ARC?

- Hoe verloopt de opvolging hier?
    - Denk eens even terug aan uw laatste consultatie. Hoe verliep die?
    - Wat vindt u dat er over het algemeen goed loopt bij de opvolging?
    - Wat vindt u dat minder goed loopt bij de opvolging?
    - Gaat u steeds naar dezelfde specialist?

        - Hoe is de relatie met de specialist?

- Wat vindt u van de opvolging door specialisten in het centrum?
    - Communicatiestijl?
    - Informatie geven
    - Voldoende tijd voor u
    - Begrijpen van de cultuur?
    - Persoonlijke moeilijke situatie
    - Seksueel getinte topics
    - Andere medische problemen?

Focus op de huisarts

- Hoe verliep uw laatste consultatie bij de huisarts? *(indien patiënt een huisarts heeft)*
- Waarvoor gaat u naar uw huisarts? (Kiest u zelf met welke problemen u naar de huisarts dan wel naar de specialist of gaat u steeds eerst naar de huisarts?
    - Telkens dezelfde arts?
    - Hoe helpt de arts u bij de opvolging/behandeling van AIDS?
- Hoe is de relatie met uw huisarts?
- Wat betekent uw huisarts voor u?
- Wat vindt u van de kennis van uw huisarts over HIV?
- Komt uw huisarts op huisbezoek?
- Hoe lang bent u onderweg naar uw huisarts
- Kan u gemakkelijk bij uw huisarts terecht? (Zijn er lange wachttijden?)

Focus op de samenwerking

- Hoe verloopt de samenwerking tussen het Aids Referentie Centrum en uw huisarts?

Topic 3 : Opinies

De Aids referentie centra kunnen het opvolgwerk onvoldoende aan. Er zal in de toekomst meer HIV- zorg door andere hulpverleners moeten worden opgenomen.

- Wat vindt u hiervan?
- Wie ziet u die taak opnemen? (huisarts, referentie arts, referentie verpleegkundige,...?)
- Over welke vaardigheden moeten deze hulpverleners beschikken?

Persoonlijke zorg in de toekomst

- Wat is voor u de beste manier om HIV-opvolging te doen?

- Hoe zou u het vinden wanneer uw huisarts u meer zou opvolgen?
    - Wat moet uw huisarts kunnen?

- Zou u liefst opgevolgd worden door uw huisarts of door een andere huisarts, eventueel aangeraden door het ARC, die meer op de hoogte is van HIV?

In 2005 werd er gestart met het opladen van een SumEHR. SumEHR staat voor Summarized Electronic Health Record. Het is een elektronische samenvatting van je medisch dossier met de minimale gegevens die een arts nodig heeft om je gezondheidstoestand snel in te schatten. Zo kan een arts die je medische voorgeschiedenis niet kent, je vlug de juiste zorg geven. In principe kan elke arts een SumEHR opmaken. In de praktijk is je huisarts die je globaal medisch dossier beheert evenwel het best geplaatst om een SumEHR te maken op basis van je medisch dossier. Mits je toestemming kan je huisarts je SumEHR delen met andere artsen. Andere zorgverleners, zoals apothekers of thuisverpleegkundigen, kunnen je SumEHR niet inkijken. Als je een andere arts consulteert, kan die meteen je SumEHR consulteren. Een SumEHR kan volgende gegevens bevatten:

- *Basisgegevens zoals geboortedatum;*
- *Gegevens van een contactpersoon in geval van noodsituaties;*
- *Risicofactoren (allergieën, reacties op medicatie, sociale risicofactoren, ...);*
- *Medische voorgeschiedenis;*
- *Actuele problemen;*
- *Medicatie die je inneemt;*
- *Vaccinaties.*

- Wat weet u over SumEHR? Had u al gehoord van een SumEHR?
- Hoe heeft uw (huis)arts gevraagd of hij uw gegevens mag delen met andere hulpverleners? (kan ook de arts van het referentiecentrum zijn)
- Heeft u vragen over wat een SumEhr inhoudt?
    - Wat vindt u van het concept van de SumEHR.
    - Welke voordelen ziet u?
    - Welke nadelen ziet u?
    - Zou u geneigd zijn uw diagnose te laten opnemen in de Summer? Waarom wel? Waarom niet?
    - Zou u geneigd zijn uw medicatie te laten opnemen in de SumEHR? Waarom wel? Waarom niet?

Wat vindt u van het concept een vaste apotheker te hebben?

- Zou u uw HAART medicatie willen gaan afhalen bij een apotheker waarbij u ook eventueel andere medicatie gaat halen?

7.3. Afsluiting

Bedanking voor uw medewerking.

Wilt u graag nog iets toevoegen aan het gesprek?

7.4. Nabespreking

Draaiboek/topiclijst aanpassen indien nodig

Interviewstijl aanpassen indien nodig

Back-up van audio materiaal maken.

Informed consent

By signing this document I declare that I have received and read this document in a proper way. I agree with the content of this document and would like to participate in this study.

I received information about the aim, length and expected effects of this study and about what will be expected from me. The possible risks and advantages of this study have been explained. I was offered the possibility and sufficient time to ask questions about the study, and I received a satisfactory answer to all my questions, including medical questions.

I agree to collaborate fully with the doctor in charge.

I have been informed about the existence of an insurance policy in case of damage that could be attributed to the participation in this study.

I am aware of the fact that this study has been approved by the independent Commission for Medical Ethics of the University Hospital Ghent and that this study will be executed in accordance with the guidelines for good clinical practice (ICH/GCP) and the declaration of Helsinki, a statement of ethical principles for medical research involving human subjects.

I can withdraw from this study at any time without any reason for this decision and without having any influence on my relationship with the researcher/doctor in charge.

By signing this document, I declare that participating in this study is voluntary:

Name of the participant: _____

Date: _____

Signature: _____

The volunteer agreed to participate in this study by signing and putting the date on this document. I confirm that I explained the aim, length and expected effects of this study to the volunteer, mentioned above:

Name of the person: _____

who informed the volunteer: _____

about the study: _____

Date: _____

Signature : _____

Code Book

P: The nurses will start from the first patient to the last one without sterilization(contaminatio,) K: I know that P: I know i was infected in that ward because i come from Uganda where when you are getting married you test(test)	The sorce of her infection is contamination in the hospital set	Putting responsabilitie in to others.	test/ Genuine
P: I know i was infected in that ward because i come from Uganda where when you are getting married you test(test) K: Yes P: When you get pregnant you test K: Yes P: When you deliver you test K: Hh P:When you go for child immunization they are testing you because they want that child to be safe in that period.(Safe child) K:You were there very controlled	The patient was allways safe	Negative	test/ Genuine
: Hh P: So i know because of the wound, that is the only time, and at that time i asked my doctor that " but they are using the same forceps(Contamination) K: Hh P: Same equipment from one person to another, they said oh! You know we are using cotton, we are cleaning K: Ya P: But you are using cotton but you are entering it in the wound, the cotton that is sterilized anyway	The same instruments were used to clean several peoples wounds which led to spread of infection from one person to another. Being in Sub Sahara she couldnt avoid it.	**Poor health care system as a source of spread of HIV infection**	Contamination

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Opvolging van HIV in de huisartspraktijk: patiëntenperspectief van de Sub-Saharaanse migranten (SAM) (Manama huisartsgeneeskunde Mallya Flotea)

Belgisch Registratienummer: B300201836723

datum	ons kenmerk	contactpersoon
11/06/2018	18/14/192	Secretariaat Ethisch Comité ethisch.comite@uza.be

DEFINITIEF GUNSTIG ADVIES

Geachte Collega,

Het Ethisch Comité van het Universitair Ziekenhuis Antwerpen en de Universiteit Antwerpen bevestigt dat bovenvermelde studie voldoet aan de criteria gesteld in de wet van 7 mei 2004 en geeft een gunstig advies dd. 11/06/2018.

De volgende bijlagen werden volgens de ICH-GCP richtlijnen door het Ethisch Comité goedgekeurd:

- CV onderzoeker
  dr. Mallya Flotea
- Informatie- en toestemmingsformulier NL aangepaste versie dd. 29/05/2018
  Versie 2
- Protocol aangepaste versie dd. 29/05/2018
  Versie 2
- Diverse
  Scriptgesprekken, versie 2 dd. 25/02/2018
  Uitnodigingsbrief, versie dd. 29/05/2018
- Vragenlijst(en) dd. 3/02/2018
  Demografische gegevens, versie 2

Patients Information

INFORMATION BROCHURE FOR PARTICIPANTS

Title of the study: HIV in primary care: patients' perspective of Sub-Saharan African Migrants (SAM).

Aim of the study: You are invited to participate in a study on the vision of people living with HIV of Sub-Saharan African origin on shared HIV care. In the case of shared care, the follow-up would partly be done by the Aids Reference Center and partly by the GP. The aim of the study is to get a better view of the patients' perspective of patients of Sub-Saharan African origin on shared care.

Description of the study/procedures: The University of Antwerp is conducting a study on the patients' perspective of Sub-Saharan African Migrants on the follow-up of patients with HIV in primary care. For this study it is important to know how patients are facing HIV care by the general practitioner. This research is part of a graduation thesis of the Master-After-Master in Family Medicine.

In Belgium, the number of people living with HIV is increasing. This increase is largely due to the recent development of highly efficient anti-HIV drugs. As a result, life expectancy has increased enormously. HIV is no longer an 'acute disease', but has become a 'chronic disease' that allows you to lead an AIDS-free life if there's a good follow-up and therapeutic compliance. Because more and more people are living with HIV, more and more people are followed up by the Aids Reference Centers. This causes a capacity problem. In the future, part of the care will have to be taken over by other care providers. As mentioned above, the researcher would like to find out what your opinion is on HIV care by the general practitioner**.**

Who can participate in the study**?:** People living with HIV of Sub-Saharan African origin, older than 18 years, who have enough knowledge of Dutch, French or English for an in-depth interview.

Number of participants: 8

Duration of the study: 55 minutes, one individual in-depth interview.

Location of the study: In a quiet space preferable for the patients**.**

Collaboration: In order to carry out a good study, it is important that you fully cooperate with the researcher and that you follow the instructions carefully.

Your participation is voluntary: The decision to participate in this study is completely voluntary. If you decide to participate, you will be asked to sign the accompanying 'Informed Consent'. You can review your decision any time without argumentation. If you decide not to participate at this study, this decision won't have any influence on the quality of your current or future medical treatment or on your relationship with the investigators.

Procedures: The study is based on an interview. The interview lasts about 50 minutes and consists of a number of open questions. You will also be asked to complete a short questionnaire of one page, which takes about 5 minutes. The conversation is recorded on audio recorder to analyze the data later.

Benefits and risks: This study doesn't offer you any personal advantages nor does it harm you. The results obtained may lead to a better understanding of the patient perspective of patients with HIV in a possible future shared HIV care.

This study was approved by an independent Medical Ethics Committee of the University of Antwerp, and will be carried out in accordance with the guidelines for good clinical practice (ICH/GCP) and the declaration of Helsinki of 2013, designed to protect people participating in clinical trials. This study is being conducted under the supervision of Prof. Dr. Vandekerckhove.

Under no circumstances should you consider the approval of the Medical Ethics Committee as an incentive to participate in this study.

Expenses and compensation for the participant: Your participation in this study does not involve extra costs for you.

Compensation: There is no compensation provided for your participation in this study.

Confidentiality and protection of personal data: In accordance with the Belgian law of 08/12/1992 and the Belgian law of 22/08/2002, your privacy will be respected and you will be granted full access to your personal data. Every fault can be adapted at your request. If you agree to participate at this study, your personal and clinical data will be collected and coded during this study. Reports in which you are identified, will not be accessible in public. If the result of this study will be published, your identity will remain confidential information**.**

Insurance: The law of May 7th 2004 concerning experiments on the human person obliges us to insure participants in scientific projects for the participation and the risk (no matter how small) they are running. The probability that you experience any damage through

participation in this study is extremely low. Should this occur anyway, which is, however, very rare, insurance was taken out in accordance with the Belgian law of May 7th 2004**.**

Contact persons in case of questions: If you want supplementary information about this study or if you have any problems or concerns, you can contact the researcher:

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