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The logo for the International Institute of Social Studies, featuring the word "Erasmus" in a stylized, cursive script.

**Peer Support and retention in HIV care for  
sub-Saharan African and Caribbean migrant  
women:**

**The Positive Sisters program in the Netherlands**

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This document represents part of the author's study programme while at the Institute of Social Studies. The views stated therein are those of the author and not necessarily those of the Institute.

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## List of Acronyms

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Therapy
SHivA	Spirituality HIVAIDS
NGO	Non-Governmental Organisation
PS	Positive Sister
WHO	World Health Organisation
UNAIDS	United Nations AIDS
PLWHIV	People Living With HIV

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## **Abstract**

Retention in HIV care is a crucial element in the effectiveness of HIV treatment and care strategies. Barriers to care exist for various key populations such as sub-Saharan African migrants in developed countries. Peer support has become an essential component in bridging the gap between formal health care services and barriers to HIV care. This research paper studies the role of the Positive Sisters peer support program in the Netherlands that focuses on migrant women from sub-Saharan Africa and the Caribbean, in retention in HIV care. The study explores the behavioural processes that influence decision making of participants towards retention and adherence outcomes and how the program interacts with these processes. The study employs a behavioural economics framework and a qualitative approach through semi-structured interviews with 30 program participants and 2 key informants. The findings suggest that despite diminishing utility to program consumption, the positive sisters program helps retain women in HIV care through a process of various elements. Three behavioural processes that threaten retention to care and adherence outcomes were identified; self-control, time inconsistency and mental models. In addition, the program is aware of the behavioural processes and the barriers to care for this key population. However, lack of adequate financial funding remains a barrier to scaling up the program and introducing new activities for program participants. Moreover, the findings of this study remain suggestive due to self-selection bias from program entry and lack of a control group to compare outcomes.

## **Relevance to Development Studies**

Informal instruments such as peer support that assist in retaining patients in HIV care are of key importance. This is because non-retention is associated with negative economic implications on an individual, household and social level. Implications include reduction in productivity and increased health care costs due to opportunistic infections that will require costly treatment. In addition, non-retention proliferates HIV prevalence resulting in increased mortality and morbidity. Therefore, studies on peer support and retention in HIV care assist in implementing policies and strategies that can prevent the negative implications of non-retention.

## **Keywords**

HIV, peer support, retention, adherence, positive sister, match, SHivA.

# Chapter 1 : Introduction

This study investigates the positive sisters peer support program which is run by an NGO, SHivA. The director of the organisation granted permission to conduct research on the PS program and interview their participants. WHO guidelines were applied on ethics in research and in designing the informed consent form for the interview participants. More detailed ethical clarifications are included in chapter 4.1.

## 1.1. Background

Development studies ordinarily focuses on challenging issues such as health care access in developing countries whilst neglecting similar issues amongst marginalised groups in advanced countries (UN 2016). Worldwide HIV is associated with developing countries whilst overlooking the global village people now live in, where migration is thriving with people moving from developing to advanced countries in search for greener pastures i.e. better work(Duckett 2000). Consequently, the migrant population often brings diseases such as HIV knowingly or unknowingly to the host country and due to economic, structural and social barriers the migrants suffer in silence (Duckett 2000).

These barriers often result in patients dropping out of treatment and this can be costly for both the patient and health care provider. Peer support programs have been introduced worldwide especially in developing countries to provide coping mechanisms for patients living with HIV. In developed countries including the Netherlands, HIV has become a controllable disease due to “highly active antiretroviral therapy (HAART)” (Deering et al 2009:603).

However, patients still experience medication side effects and stigma surrounding HIV and AIDS leading to mental and psychological problems such as stress, anxiety and depression. This often leads to poor adherence and a decline in patient retention in treatment. As a result, peer support has become increasingly important in HIV health care to improve retention in care and adherence for patients living with HIV (Deering et al 2009).

### ***1.1.1. Problem***

Women from sub-Saharan Africa are the most infected and affected with HIV little research has been conducted on how this focus group copes with HIV in developed countries (Schoepf 2001). In the Netherlands women of sub-Saharan African and Caribbean origin have the highest HIV prevalence amongst all women living with HIV (Van Sighem et al 2016). These women find it difficult to be open about their reproductive health with their doctors and health care providers due to cultural and religious barriers. Consequently some drop out of HIV treatment and care (Van Sighem et al 2015).

Dropping out of HIV treatment is a widespread problem, especially in Africa as pointed out by Geng et al (2010) in their study on understanding reasons and outcomes for patients who dropped out of HIV treatment. They followed up patients who had dropped out of treatment within the first year of therapy in a Ugandan province and conducted interviews with some of them and their close informants.

Their main findings suggest that most patients are not retained in HIV care due to “social or structural” reasons ranging from “problems with transportation, finances, and work/child care responsibilities” (Geng et al 2010:6). A similar study in Johannesburg South Africa by Dalal et al (2008) yielded similar results with resource constraints being the major contributing factor to non-retention in HIV care. (Dalal et al 2008). Similarly findings from Rosen et al (2007) suggest that retention in HIV care is a problem in most African countries and they conclude that programs that can aid retain patients in care are crucial.

Market mechanisms are not always successful in improving well-being and welfare as far as health care is concerned because they create winners and losers (WHO 2008). Losers in this case are usually vulnerable populations marginalised from formal health care such as drug users and minority ethnic groups. Non-market mechanisms such as peer support programs bridge this gap by including these populations into health care access (WHO 2008). Formal health

care alone is unable to deal with the growing number of long term chronic illnesses, hence the need for social support systems such as peer support (Mignone et al 2007).

### ***1.1.2. Intervention***

Peer support is a concept rooted in the social support theory. Mead et al. (2001) define peer support as the procedure by which individuals with comparable experiences, reassure and assist each other to continue on the path of healing. Peer support also allows for joint empowerment when the interaction between 2 individuals develops and they get affiliated with one another. This opens room for deeper discussion, permitting for conversations on topics considered taboo (Mead et al 2001).

During stressful moments, individuals rely on social support for strength. When an individual is diagnosed HIV positive, it becomes a stressful period in one's life and they need every support they can get to cope with the diagnosis. Therefore, peer support can be used as coping mechanism for HIV patients undergoing HIV treatment (Stewart and Tilden 1995).

Peer support for individuals living with HIV offers a safe environment for participants as they get to be open about sensitive topics such as sex and romantic relationships. The stigma surrounded by the sexual nature of acquiring HIV makes it difficult for patients to disclose their status to friends, family and sometimes partners.

### ***1.1.3. Research objectives***

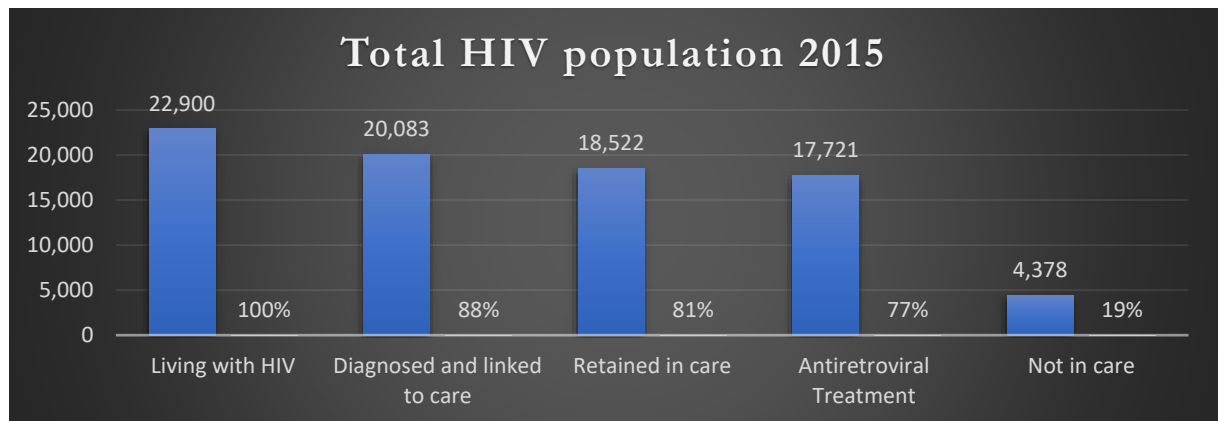
This research paper aims to investigate whether peer support helps retain migrant women in HIV care, focusing on the Positive Sisters peer support program in the Netherlands.

## 1.2. HIV in the Netherlands

The Netherlands is a country with a diverse population, from various parts of the world, different religions, cultural values and norms (World Population Review 2017). In the Netherlands, heterosexual women are the second largest group of HIV patients, with the highest number originating from sub-Saharan Africa (Van Sighem et al 2016). In 2016, 39% of the total infected by a heterosexual transmission were from sub-Saharan African and Caribbean origin (Van Sighem et al 2016).

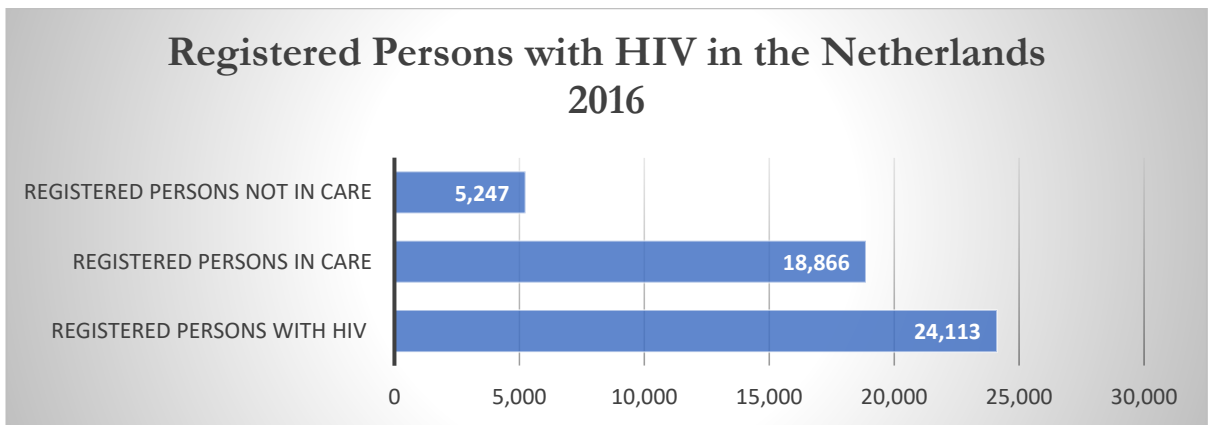
From these key populations, women are the most infected with 46% of the total HIV infected women in the Netherlands originating from sub-Saharan Africa and the Caribbean (Van Sighem et al 2016). Moreover, this key population experiences more seclusion and stigma in comparison to white Men who have Sex with Men (MSM) (Sumari-de Boer 2012). This is usually because of various cultural norms and religious factors stimulating several consequences for being HIV positive (Stutterheim et al 2011).

**Figure 1: Total HIV population in the Netherlands 2015**



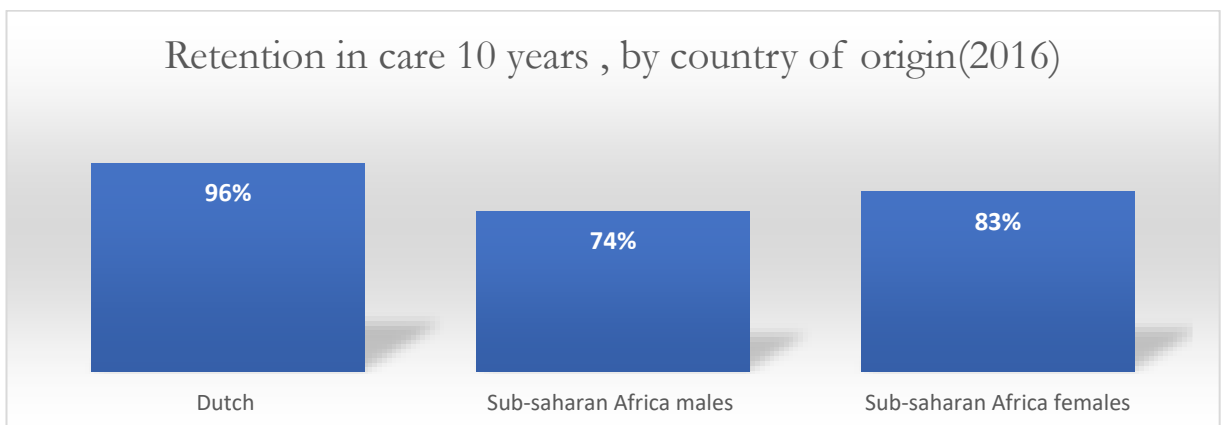
*Source: (Van Sighem et al 2016)*

**Figure 2: Registered persons with HIV 2016**



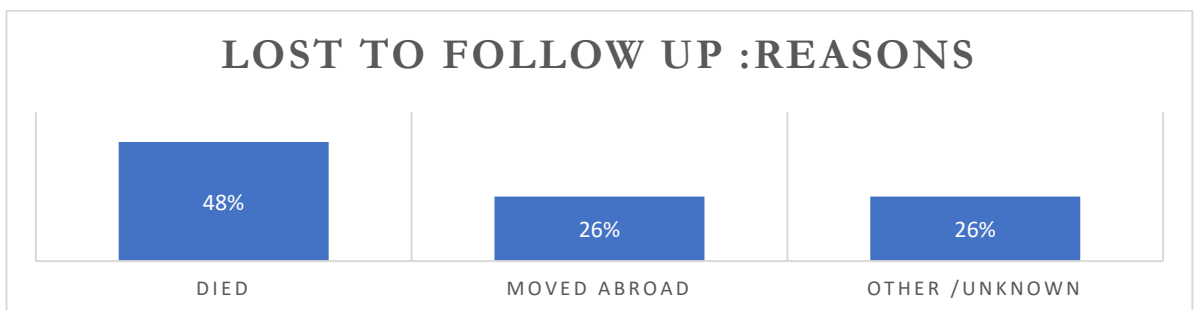
Source: (Van Sighem et al 2016)

**Figure 3: Retention in HIV care by ethnicity**



Source: (Van Sighem et al 2016)

**Figure 4: Lost to follow up reasons**



Source: (Van Sighem et al 2016)

Figure 1 above shows a brief overview of the registered HIV population in the Netherlands in 2015. The number of HIV persons registered and not in HIV care rose in 2016 by 5.3 and 16.6 percent respectively, as shown in figure 2. Figure 3 shows that patients with sub-Saharan African origin are less retained in care in comparison with Dutch patients. For patients who are not retained in care, 48% died, 26% moved abroad and 26% is lost to follow up for unknown reasons (Van Sighem et al 2016).

### ***1.2.1. HIV institutions in the Netherlands***

There are 30 health institutions<sup>1</sup> that specialise in HIV care in the Netherlands, 4 of which are children hospitals. Individuals living with HIV can seek care through referral from the family doctor (Van Sighem et al 2016). There is community reproductive health care centres such as SOA AIDS, sexually transmitted disease (STD) centres where individuals can undergo free testing and counselling. If found HIV positive patients are referred to a hospital that specialises in HIV care and are required to inform their health insurance to cater for the health care costs (Van Sighem et al 2016).

### ***1.2.2. Treatment and compliance***

In the Netherlands, residents are required to have a health insurance and asylum seekers are also eligible for health insurance but individuals without legal residence in the Netherlands are not entitled to a health insurance (Van Sighem et al 2016). However illegal migrants with a chronic illness are entitled to care, the costs of care for patients incapable of paying are subsidised by the National Health Institute (National Health Institute 2017).

The patient receives care from an HIV specialised doctor who gives detailed results of the blood work and writes out prescriptions. Right after the doctor's consultation, patients consult the nurse consultant whom they can speak to about personal and social life. If the patient has any other concerns the nurse

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<sup>1</sup> A map of the Netherlands showing various HIV specialised hospitals is included in appendix 1. HIV Monitoring Accessed from <<https://www.hiv-monitoring.nl/english/medical-professionals/hiv-treatment-centres/>>.



refers them to another specialist for example patients are referred to the social worker when undergoing financial problems or psychologist if they need a deep conversation with a professional (Van Sighem et al 2016). However some patients need support beyond the hospital due to cultural and language barriers in healthcare facilities, they are referred to a peer support program.

## **Chapter 2 : The Positive Sisters peer support program**

The Positive Sisters peer support program was initiated by SHivA (Spirituality HIV and AIDS) a non-profit organisation based in Amsterdam, the Netherlands that focuses on HIV issues affecting migrants. The researcher has been a volunteer of SHivA since 2013 and was granted permission to conduct research on the PS program<sup>2</sup>. The program started in 2011 focusing on migrant women from sub-Saharan Africa and the Caribbean to provide support, empowerment and bridging the gap between formal health care and barriers to HIV care faced by the women. SHivA started working with 6 hospitals and the number has gradually increased to 23 hospitals in different cities and provinces of the Netherlands (Stichting SHivA 2016).

The PS program trains women to provide other women with emotional and informational support, also focusing on faith and spirituality. In addition, the program organises other activities such as workshops on pregnancy, HIV medication use, status disclosure to family, partner and friends, financial and legal matters. The positive sisters program engages with a variety of women, documented and undocumented migrants and women living in asylum centres (Stichting SHivA 2016).

The main goals of the PS program are; to improve the self-esteem of participants, increase the self-reliance of participants, and provide additional and recent information on HIV, emphasize the importance of proper treatment adherence and patient retention (Stichting SHivA 2016). The program matches newly HIV diagnosed women with peer support so that they have support from the beginning of their journey with HIV (Stichting SHivA 2016).

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<sup>2</sup> Information on ethics and positionality of researcher is included in section 4.1 and 4.1.1.

## 2.1. Selection Process and matching criteria

The coordinator of the program is in contact with the HIV specialised hospitals nationwide and it is at these hospitals that women are offered to join the program. The HIV nurse offers information about the program to the women and if willing to join, the coordinator of the program contacts them for a short meeting. The women are invited to some of ShivA's activities and if willing the women sign up for peer training. The peers undergo training in groups of about 10-12 women over a period of 3 months, with a total of 6 days and one weekend. The women receive a certificate and a volunteer contract after the training and they are referred to as *positive sisters* and the women they support *matches*. SHivA bears the training costs per woman and each positive sister receives 120 euros per year for their voluntary work and other related costs such as travel expenses and telephone vouchers. (Stichting SHivA 2016).

Their names are submitted to HIV specialised hospitals where the HIV nurse offers information about the PS program to newly diagnosed patients and existing patients not yet enrolled in the program. At the hospital when a woman needs a peer, the nurse contacts SHivA and they discuss the possibilities of matching. If the patient is willing, a peer-match is created and participation is free of charge. The match criteria are based on age, language, religion, country of origin, level of education and place of residence in the Netherlands. The first meeting between a positive sister and a match is administered at the hospital of the match with the presence of the nurse for introductions. If the match is comfortable both women exchange contact details for further contact.

Thereafter the positive sister contacts the match twice a week by telephone or face to face to provide support according to the needs of the match. A positive sister can support several matches, depending on her capacity to do so. The positive sister can invite the match to SHivA activities such as workshops, HIV+ women's day so that the match can interact with other women and not over depend on her positive sister. The positive sister reports the progress or problems with the match to the PS program coordinator (Stichting SHivA 2016).

The positive sister supports her match /matches for a period of six months and officially close the mentorship with a meal. However, they can continue to communicate if a friendship develops.

### ***2.1.1. Training of Positive Sisters***

The positive sisters undergo an intensive training for peer supporters for 6 days, the training takes place at the SHivA offices in Amsterdam. The training aims to give a positive outlook on life with HIV, providing speaking and listening techniques and self-reflection towards growth of being a volunteer (Results in health 2016:9). The training focuses on 3 goals for a match.

- I am going to live, I will not die, and I can get old with HIV.
- I take my medication. Medication is an ally in my life, not a problem.
- I will go on with my life, HIV is not a disaster, I will empower myself.

One day during the training processes is dedicated towards psychological problems encountered by women from sub-Saharan Africa and the Caribbean that are different from the Western culture. The training also emphasises on spirituality and faith since most women come from religious backgrounds. The training emphasises on 3 support techniques:

- “I listen carefully, I encourage her to tell.”
- “It is her life, her happiness, I do not take it over from her”
- “I do not give her good advice, I give her self-confidence.” (Results in health 2016:10).

The women also receive further training to discuss certain scenarios that the positive sisters encounter during the match process and brainstorm solutions to various issues (Results in health 2016). SHivA has trained to date 45 positive sisters and 149 regular matches have been supported by a positive sister (Results in health 2016).

## 2.2. Research questions

### 2.2.1. Key research question

*Does the Positive Sisters program help retain women in HIV care?*

### 2.2.2. Sub questions

- Does the program address mental illness (stress, depression and anxiety)?
- Does patient retention differ between positive sisters and matches and by different individual characteristics?
- Which behavioural processes<sup>3</sup> influence the health decision making process of the positive sisters and matches and how does the program interact with them?

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<sup>3</sup> Behavioral processes refer to cognitive and emotional biases that affect the decision making process of individuals.

## **Chapter 3 : Literature review**

There have been several studies on peer support and health outcomes amongst people living with HIV (PLWHIV) and most of them have been conducted in sub-Saharan Africa. There are however a few studies on peer support and health outcomes of sub-Saharan African females living in developed countries. This chapter will review some of the relevant literature to date that has focused on retention, adherence, barriers to HIV treatment and care and peer support in HIV care.

### **3.1. Retention and adherence: Implications**

Retention in HIV care refers to sustained appointments and visits to health care providers denoting the “continuum of HIV care” (Stricker et al 2014:466). Adherence refers to the degree a patient complies with recommended HIV treatment. These 2 concepts are extremely important in HIV care and treatment in order to control morbidity and mortality of HIV patients. In the political declaration on HIV and AIDS (2016), UNAIDS and WHO have highlighted the importance of retention and adherence for effective HIV treatment (UNAIDS 2016).

Dodds et al. (2003) investigated the barriers that hinder adherence and retention to care for females under the age of 25 and established that females have “gender specific” issues that further obstruct retention and adherence (Dodds et al 2003:39). The study further concluded that HIV positive females require additional support to cope with issues surrounding the disease (Dodds et al 2003). Some patients might attend all their doctor’s visits but not adhere well to treatment that is why it’s important to understand the effects of non-retention and non-adherence (Stricker et al 2014). Furthermore poor adherence to treatment and non- retention to care can lead to further transmission of the virus, resulting in a higher prevalence (Stricker et al 2014).

In addition HIV is related to mental health problems due to medication side effects, social stigma surrounding the disease and PLWHIV tend to suffer from

mental health issues such as depression in comparison to HIV negative individuals (Zuniga et al 2016). The findings by Zuniga et al (2016) suggest that various levels of depression in HIV positive individuals lead to different retention outcomes. For instance, patients within their study who were experiencing “negative moods” were more likely to miss a doctor’s visit, hence more attention should be given to these individuals (Zuniga et al 2016:34).

Non-retention and non-adherence have negative economic implications on an individual, household and societal level such as increased health care costs, reduced income and productivity due to illness or death (Stricker et al 2014). Poor adherence and non-retention reduce treatment effectiveness and patients may suffer to drug resistance. As a result, patients and caregivers incur increased health care costs due to increased illness and need for second line HIV medicines which can be very costly. The cost incurred per patient or household depends on the health care arrangement of a country (Stricker et al 2014).

Further negative implications include reduced productivity and income due to illness. The patient can report more ill days from work, reduced working speed or totally stop working due to opportunistic illnesses caused by drug resistance (Stricker et al 2014). Consequently, there is reduced income for the patient or household and increased financial burden on household members who depend on the patients’ income.

Several studies have researched the cost implications of adherent vs non-adherent patients and their findings suggest that there are higher costs of HIV care associated with poor adherence and non-retention. Knobel et al (2000) investigated the costs of non-retention in Barcelona and concluded that patients who had over 90 percent retention recorded about 4 hospitalisation days compared to 15 for patients with low retention (Knobel et al 2000). Similar findings from (Paterson et al 2000; Giordano et al 2007) indicated fewer hospitalisation days associated with high retention and adherence levels. Studies by (Long et al 2010; Nachega et al 2010) in South Africa investigating the effects on ART on HIV healthcare costs concluded lower monthly costs for patients with higher adherence in comparison to those with low adherence.

The improvement of ART reduces morbidity and mortality in HIV patients, therefore early entry and retention into care is required for optimum effectiveness of ART (Thompson et al 2012). However certain behaviours and barriers to care exist for disadvantaged groups in society hence the need for extra support beyond formal health care. The subsequent sections will review literature on the barriers to HIV care for sub-Saharan African and Caribbean women in developed countries. Literature on peer support and health outcomes; retention and adherence will also be reviewed.

### **3.1.1. Barriers to HIV care for sub-Saharan females in developed countries**

This section will highlight barriers to HIV care encountered by sub-Saharan African and Caribbean women through a review of literature. These are important to know and understand because they affect behaviour towards adherence and retention to HIV care. There have been several studies directed towards HIV and the social and economic problems created as a result.

According to Nelson (2002) “ethnic and racial disparities” exist in HIV care and they act as barriers to care (Nelson 2002:666). Tobias et al 2007 indicate that African Americans are the most infected and affected with HIV in the United States. The study indicated that they often face barriers ranging from financial, legal to distrust in the health care system (Tobias et al 2007).

Stutterheim et al (2011) examine HIV status disclosure as a barrier among the HIV positive African and Afro-Caribbean population in the Netherlands and find that stigma is the leading reason for non-disclosure ((Stutterheim et al 2011). Similar findings emerge from Fakoya et al (2008) investigating the barriers to HIV testing for migrant black Africans in Western Europe. The findings deliver insight on the challenges faced by migrants in Europe where HIV care and stigma are concerned (Fakoya et al 2008).

Doyal and Anderson (2005) implemented a qualitative study on HIV positive females from sub-Saharan Africa living in London. Their findings indicate that



although the women in their sample were grateful for the advanced health care provided in London compared to their country of origins, they felt lonely and lacked social support. In their study, the women cited *legal* reasons as one of the drivers of stress and anxiety which affected their decision-making process towards adherence and retention. Another finding from this study is that women reported *stigma* as a challenge in job-seeking and social relationships and being in an unfamiliar cultural setting also poses challenges (Doyal and Anderson 2005).

Similar findings transpire from the research by Arrey et al (2016) amongst HIV positive sub-Saharan African females living in Brussels, Belgium. In their research females faced stigma and discrimination from the Belgian society because HIV is regarded as a “foreign disease” in that society (Arrey et al 2016:585). A key finding in their study is that stigma mainly stems from health care situations through “delayed or denied care, excessive precautions, blame and humiliation” (Arrey et al 2016:578). As a result, the women suffer from stress, they do not disclose HIV status and have poor adherence and retention outcomes. These findings are very essential in understanding the behavioural reasons behind adherence and retention outcomes of HIV positive sub-Saharan African migrant females in developed country settings.

Stigma, discrimination, together with cultural, socio-economic and language barriers to HIV/AIDS prevention and care, make some of Europe’s migrant and ethnic minority groups especially vulnerable. Therefore, understanding the root causes of the barriers of HIV care in Europe’s migrant groups and ethnic minorities is vital for fostering suitable preventative healthcare services, and enlightening public health policy (Del Amo et al 2004).

### **3.1.2. Peer support and health outcomes**

Deering et al (2009) implemented a peer support model aimed at supporting HIV positive sex workers (females) who use drugs in Vancouver. They analysed the effects of peer support on adherence levels, looking at both self-reported adherence and pharmacy reports. They concluded from the intervention that peer support has a positive effect on adherence from the results of

improved and steady adherence amongst participants during the program (Deering et al 2009).

They further conclude that peer support has a short-term positive impact on adherence outcomes, long-term success is not certain due to risky behaviours that might affect adherence results (Deering et al 2009). Although the intervention was not entirely focused on women of sub-Saharan African origin and concludes uncertain long-term effects. It still serves as a benchmark for how peer support influences health outcomes for marginalised groups in society.

Similar findings from Been et al (2016) who study risk factors associated with non-adherence to anti-retroviral therapy for immigrants living with HIV in the Netherlands and conclude that there is need for peer counselling and mentorship programs to address the issue of stigma(Been et al 2016).Correspondingly ,Gras et al (1999) find a potential risk of spread of STD's amongst ethnic groups in the Netherlands and emphasise the role of peer support programs in reducing the HIV prevalence amongst these groups(Gras et al 1999).

An intervention by Simoni et al (2009) amongst HIV outpatients in a Seattle HIV clinic also conclude short-term health benefits and further approaches to sustain long-term benefits. They measured the impact of peer support and pager messaging compared to usual health care on adherence and health outcomes. They reported increased self-reported adherence in the short-term due to peer support (Simoni et al 2009). Vyavaharkar et al (2007) also indicate similar findings in a study on the impact of peer support on HIV positive women with depression in Western United States.

Their findings suggest that peer support improved adherence especially in the short term but has a better impact if combined with other coping strategies such as religious activities (Vyavaharkar et al 2007).Similar findings stem from the research Govindasamy et al(2014) who identified studies illustrating various interventions targeted towards improving retention in HIV care. Their findings deduced that an integration of peer support into formal health care systems results in improved retention in HIV care (Govindasamy et al

2014). These findings serve as a guide on the importance of peer support in HIV care.

McCallum et al (2014) conducted a research for The Ontario HIV Treatment Network (OHTN) on the effectiveness of peer support for improving adherence and drop out of peers. Their research summarised that interventions geared towards specific groups such as African and Caribbean women where HIV is highly stigmatised significantly improve future adherence outcomes. They further concluded that peer programs are beneficial to both parties, hence commonality between the two is required for the match to work (McCallum et al 2014).

Martijn et al (2004) investigated the effects of HIV and AIDS prevention programs by lay health workers for migrants in Rotterdam, Netherlands focusing more on males from Moroccan and Turkish backgrounds. They employed a qualitative approach of interviews and concluded that the programs resulted in safe sex practices amongst the focus group (Martijn et al 2004). This study however excludes women and lacks to give insight on the sex practices of females of those backgrounds. Rotheram-Borus et al (2014) study the impact of HIV peer mentors on maternal and infant wellbeing in South Africa through randomisation and conclude that women living with HIV benefit from peer mentors (Rotheram-Borus et al 2014).

Results in Health, an international health organisation based in the Netherlands evaluated the Positive Sisters mentorship program in 2013. The evaluation used a qualitative approach and disclosed positive outcomes in terms of empowerment, self-esteem and HIV status acceptance (Results in Health 2013). Although the evaluation revealed positive effectiveness of the program, there is lack of knowledge on dropout of women from HIV therapy and impact of program on economic outcomes remains unknown.

Most of the literature is less focused on sexual behaviours of migrant women and the role of peer support programs on HIV positive migrant women living

in the Western countries such as the Netherlands. I aim to analyse if the Positive Sisters program helps retain women in HIV care.

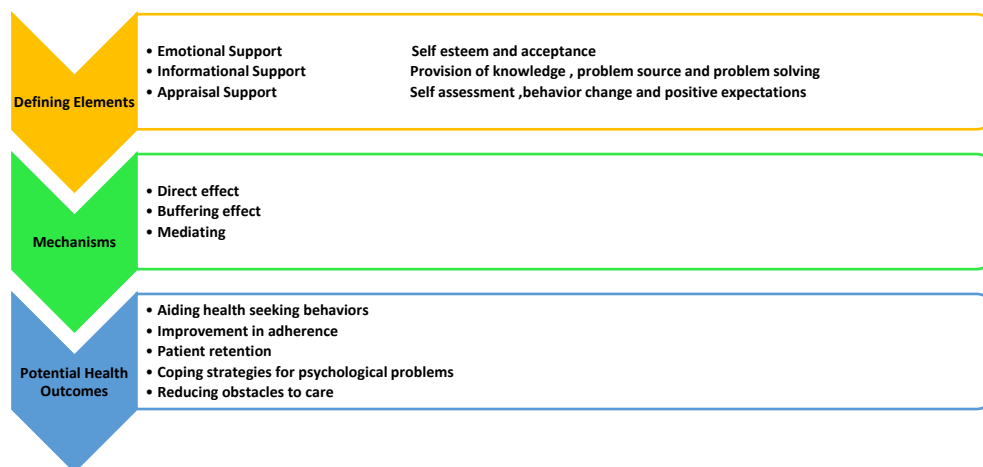
## 3.2. Conceptualisation

### 3.2.1. Peer support in health care

Peer support as a concept can be defined “as the giving of assistance and encouragement by an individual considered equal” (Dennis 2003:323). A peer support system is a source of assistance that requires at least two individuals with the same health condition, age, ethnicity and stressors.

Peers are chosen to understand problems and concerns of the target audience in a manner that health professionals and other social networks cannot. Hence the training of peers should present a clear framework of goals, objectives and methods that utilise “experimental knowledge” to gain an exceptional grasp of the program (Dennis 2003:326). Figure 5<sup>4</sup> below gives an illustration of the peer support concept according to Dennis (2003), ranging from the defining elements, mechanism and potential health outcomes.

**Figure 5: Peer support in health care (Dennis 2003)**



*Source: Dennis (2003)*

<sup>4</sup> Figure was constructed by author based on information from Dennis (2003).

### ***3.2.2. Defining elements of peer support***

Peer support can be conducted in diverse ways (individual or group setting), different settings (home, hospital, and organisation), distinct roles (counsellor, leader) and different structures (Dennis 2003). The concept of peer support is rooted within three defining elements; emotional, informational and appraisal support (Dennis 2003).

#### **3.2.2.1. Emotional Support**

Emotional support is centred on enhancing self-esteem of patients through “caring, encouragement and attentive listening” (Dennis 2003:325). This type of support fosters emotional growth and acceptance for the individual being supported.

#### **3.2.2.2. Informational Support**

Informational support focuses on information seeking through recommendations, feedback and guidance. This allows for delivery of new knowledge connected to problem causes and problem solving (Dennis 2003).

#### **3.2.2.3. Appraisal Support**

Appraisal support centres on provision of information related to self -assessment of certain behaviours. The mechanism is through motivational techniques such as encouragement and assurance of positive results allowing individuals to have positive future outlooks (Dennis 2003).

### ***3.2.3. Models of peer support***

There are three models of peer support; direct effect model, buffering effect model and mediating effect model.

“Founded on this mutual identification, shared experience, and sense of belonging, there is evidence to suggest that peer support positively affects psychological and physical health outcomes” (Dennis 2003:326).

#### **3.2.3.1. Direct effect model**

Within the direct effect model, peer support enhances participation and integration by creating a sense of community and reducing loneliness. The peer support improves the individual's self-esteem through interaction with peers in similar situations, improving mental state of mind and overall well-being. There is provision of information related to health care services and behavioural change towards improved health outcomes. This information further leads to prevention and advancement of illness (Dennis 2003).

#### **3.2.3.2. Buffering effect model**

Peer support within this model functions as a coping mechanism against psychological stressors. Peer communication safeguards the impact of stress on overall well-being through problem discussion and solving methods which lessen the burden of the problem. It also permits behaviour change such as how the individual's interpretation of the problem and blaming oneself for the problem (Dennis 2003).

#### **3.2.3.3. Mediating effect model**

This model foresees that peer support is mediating concept that stimulates "health through emotions, cognitions and behaviours" (Dennis 2003:327). Peer interaction achieves this by reassuring positive outcomes and expectations and providing knowledge through role model experiences. Various coping mechanisms are presented to promote positive behaviours and improved well-being (Dennis 2003).

### **3.3. Behavioural processes in health decision making**

This research study will employ a behavioural economics perspective. HIV as an area of focus, is often associated with risky sexual behaviours and is highly stigmatised. In the Netherlands specifically, the PS peer support program is a form of a behavioural experiment where HIV positive women are faced with a set of choices, to join the peer support program or not; to continue HIV therapy or dropout. This program demonstrates different behavioural elements

that shape decisions of participation on both the positive sister and the mentored women, for example peer influence. The voluntary nature of program entry, reflects self-selection.

The peer-support program's objective is to empower women, however certain behaviours from the positive sisters might influence retention in care, positively or negatively. Retention in care and adherence are the primary outcome variables. Secondary outcome variables will include mental health (stress, anxiety and depression).

The "economic man" thinking expects individuals to be rational especially where health is concerned but people do not always act rational (Henrich et al 2005:795). People come from diverse backgrounds, cultures, structures, religious values which influence and shape their perceptions on HIV (Henrich et al 2005). Since people do not behave in a homogenous fashion, health program managers need to have a clear understanding of why people behave the way they do, given a specific context.

People do not always act in a way they are supposed or expected to due to several reasons that can be explained through certain behavioural concepts. Peer support is a tool that can be used to enhance behaviour hence it is important to understand why women living with HIV act the way they do and how they perceive peer support. The positive sister's peer support program aims to empower women through interaction with peers in a similar health situation. The program ought to keep into consideration the underlying behavioural elements that compel women to behave in a certain way whilst living with a chronic illness.

The psychological systems 1 and 2 affect the choices individuals make daily. There are two systems with different competences that affect decision making in individuals; systems 1 and 2. *System 1* has a reflex function, it is "automatic" which is fast and expressive (Kahneman 2011:20). *System 2* possesses a contemplative function which is slow, logical, and allows for profound assessment. System 2 is responsible for "controlling thoughts and behaviours" (Kahneman

2011:20). Either systems can be stronger within different individuals, for some system 1 is stronger whilst for others system 2 dominates. In most cases system 1 governs the thinking of individuals and individuals need to discover situations where system 2 can be used.

From the onset women are confronted with a choice, to join or not to join the positive sisters program. This choice could be an individual or collective decision, individual decision when the woman is not pressured by other factors and collective probably due to influence from a partner or friend. Women also make choices on adherence, compliance and continuation with HIV treatment. The women who decide to join are interested and enthusiastic about what the messenger conveys to them concerning the program. Individuals are “heavily influenced by who communicates information” (Dolan et al 2009:19). In the results section, behavioural processes that influence the decision making process of program participants, will be identified and how the program interacts with these processes.



## Chapter 4 : Ethics, Study design and Methods

### 4.1. Ethics

Research on sensitive health topics such as HIV and AIDS requires strong ethical consideration. Ethics embrace issues of right and wrong conduct and responsibilities attached to data collection involving human beings (WHO 2015). Ethical problems and dilemmas are inherent in health and social research dealing with vulnerable and marginalised groups. Ethics seek to address questions of morality and guide individuals to conduct research and behave from a moral angle (Holloway and Galvin 2016).

The author has been affiliated with SHivA since 2013 as a volunteer for the NGO. The director was approached for permission to write the research paper on the positive sisters program. The director granted permission to interview women involved in the PS program and for the research paper to be published on the University online website. In addition the director and the researcher discussed ethic principles to safeguard the interview participants. The principles included purpose of research, respect for confidentiality and anonymity, benevolence, informed consent, privacy, right to withdraw, voluntary participation, non-judgemental behaviour towards participants. These ethic principles are established to protect and safeguard the rights of participants (WHO 2015).

An informed consent<sup>5</sup> form was designed following the guidelines of WHO, this is attached in appendix 3. From the list of participants in the PS program, they were contacted by telephone about the research and asked whether they wanted to participate in the interviews. Women who agreed to participate were provided with a detailed purpose of research, informed consent form to sign and right to withdraw from interview.

Key informants that were interviewed include a nurse from the HIV team at The Hague HMC Westeinde hospital and a key informant from SHivA. They were

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<sup>5</sup> Detailed informed consent form attached in appendix 3.

contacted by email explaining research purpose and to make an appointment for the interview. Key informants were also provided with an informed consent<sup>6</sup> form and the same principles mentioned above were applied to their interviews.

#### **4.1.1. Positionality of researcher**

The has been associated with SHivA as a volunteer for 4 years hence most volunteers, positive sisters and matches know her from SHivA programs. As a researcher the positionality of the author made it easier to contact positive sisters and matches. The positionality of the author, being a migrant sub-Saharan African female who is connected to SHivA also influenced the trust between participants and me because she is not an outsider to them. The author was however aware that her positionality could affect the impartiality of the research. The author had to take a step back and take a researcher's perspective, not an employee's perspective. Therefore the author approached the study from a researcher's perspective in designing research questions, interview questions and results analysis.

## **4.2. Methodology**

For this research, a qualitative approach is employed using open ended interviews and a nominal 5-scale questionnaire. This was to allow for a natural flow of the conversation and thematic coding of results allowing for constructions of charts and figures (Holloway and Galvin 2016). The data collection process was between July and October 2017. A list of possible participants with their contact details was provided by the NGO, SHIVA and an informed consent form was signed for confidentiality and anonymity. To be eligible for the research women had to be HIV positive and on anti-retroviral therapy, over 18 years old, living in the Netherlands for the past year, enrolled in the Positive Sisters program, sub-Saharan African and Caribbean origin.

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<sup>6</sup> Detailed informed consent form for key informants attached in appendix 3(WHO 2017).

Women were provided with a detailed purpose of the study and an informed consent form and could withdraw from the interview if uncomfortable at any time during the interview. Interviews were face to face and were undertaken in either English or Dutch depending on the preference of the participant. The researcher filled in the questionnaire herself and made notes from interview questions allowing for coding and thematic analysis. Some interviews were tape recorded depending on the preference of the woman and only 3 women agreed to be recorded where 1 of the 3 decided to stop recording midway. Reasons for not recording included trust issues, women wanted to remain anonymous and general fear that the recording would end up elsewhere. The women did not want their voices to be recognised elsewhere because of the sensitive nature of the subject. Although they had been assured that the recordings were strictly for academic purposes and would be destroyed afterwards. For some fear stemmed from HIV status disclosure; them it was because they have not yet disclosed their status to anyone hence the thought of recording was daunting.

Nearly 70 percent of women who were approached to participate in the study agreed and finished the whole interview. Those who declined participation stated reasons of anonymity, confidentiality, stigma and lack of interest. Five women who had initially agreed to be interviewed later withdrew due to family tension other commitments. Interviews lasted between 1 and 2 hours and were conducted either at the hospital canteen or participant's home depending on the living situation and preference of the woman. Women living outside of The Hague were provided with transportation costs if needed and no other financial incentive was offered.

The first part of the interview covered basic demographic questions such as age, marital status, residence status, country of origin, legal status etc. Subsequent sections covered questions about experience with the Positive Sisters program and certain cases were presented to assess behaviour. Tape recorded interviews were transcribed verbatim allowing for thematic review of results. Transcripts were coded according to different themes, to allow construction of

graphs, charts, explain conceptual frameworks and perform deep qualitative analysis. The sample of successfully interviewed participants contains 30 women comprising of 16 Positive Sisters and 14 Matches. 14 Positive Sisters had their corresponding matches interviewed and 2 Positive sisters did not have a match who was interviewed.

Key informants were also interviewed, and these comprise of a nurse from the HIV team at the Haaglaanden Medical Centre hospital in Den Haag and the director of SHIVA, the pioneer of the Positive Sisters project. The interview with key informants comprised of open ended interview questions. The interview with the nurse from the HIV team aimed at obtaining information on actual recorded adherence and patient retention of the women from my sample who receive care from the corresponding hospital. The interviews with key informants intended to gain deeper understanding of the role of peer support for ethnic minority women from the perspective of health professionals in the formal and informal health care settings.

Although this does not cover the whole sample of women in the PS program and connected hospitals, the information obtained provides insight into the overall situation at hand.

### **4.3. Data and Descriptive statistics of sample**

The sample consists of 30 participants, all HIV positive migrant females comprising of 16 positive sisters and 14 matches. One positive sister used to be a match and later decided to be a positive sister because she wanted others to reap the benefits she had also reaped especially in the initial support stages. One positive sister in the sample is now an employee of the SHivA, assisting in the supervision and organising the smooth running of the positive sisters-match relationships and liaising with various hospitals about the program<sup>7</sup>.

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<sup>7</sup> Detailed figures of descriptive statistics included in appendix 2.

Most women in the sample, originate from East Africa (40%)<sup>8</sup>, the least originate from Southern African countries whilst 30 and 20 percent originate from the Caribbean and West Africa respectively. The sample comprises of women between the ages of 24 and 61, with about 37 percent of the sample having an age of between 31 and 40 years and the mean age is 35.

The highest level of education attained with most respondents in the sample is high school with 57 percent of participants, 33 and 10 percent have attained college and university level education, respectively.

The sample comprises of both legal and illegal migrants.60 % of the sample carries a legal status, 10 percent an illegal status and 30 percent is seeking asylum and living in refugee seeking centres. It is important to note that all women in asylum seeking procedures, comprises of only matches, no positive sisters within this category.75 percent of the sample has disclosed HIV status to either partner, family member or friend and 25 percent has not due to stigma reasons.

The 25 percent non-disclosure also comprises of only matches. 17 percent of the sample is married and living together in the Netherlands and have disclosed HIV status to husband.10 percent of the women live with their partners and have disclosed HIV status.23 percent have boyfriends and 30% of this sample has not disclosed HIV status to their boyfriends. 17 percent of the women have casual relationships.33 percent of the women are not involved in any romantic relationship and have also not disclosed HIV status to anyone.

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<sup>8</sup> All figures reported in percentages, based on a sample of 30 participants.

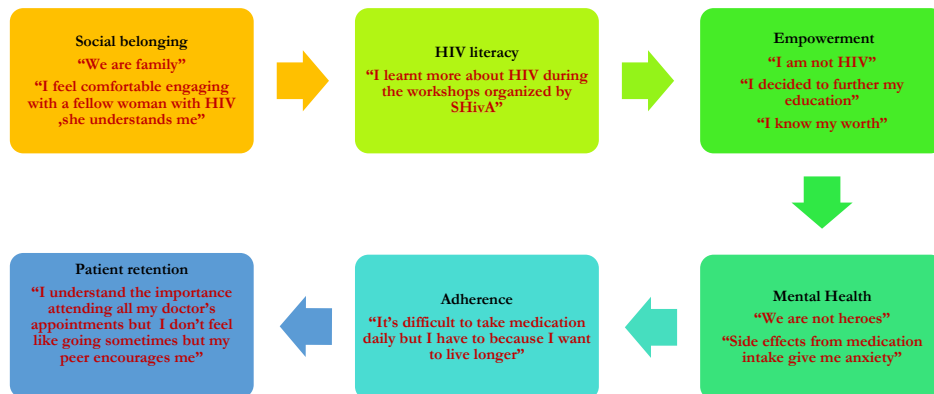
## Chapter 5 : Results

Several themes arise from the interviews conducted with the women and key informants. This chapter will report the results from the interviews conducted by positive sisters, matches and key informants<sup>9</sup>.

### 5.1. Pathway by PS<sup>10</sup> program towards retention in HIV care.

The results from the positive sisters and matches indicate that the positive sisters program does help with retention in HIV care through various mechanisms. The availability of the program does not guarantee retention in care, it needs to be accepted and various mechanisms need to work together for the retention goal to be achieved. Figure 6 below demonstrates the pathway through which the PS program moves towards retention in HIV care for its participants. The pathway emerged from the results given by the respondents, under each element there are quotes from the respondents that relate to the element.

Figure 6: PS program pathway to retention in HIV care



Source: Interview data (July, August, September 2017)

<sup>9</sup> Quotes from respondents do not contain detailed information and reference of the participants due to confidentiality agreement.

<sup>10</sup> PS refers to Positive Sister.

### 5.1.1 Social belonging

All the respondents disclosed that the program provides them with a *sense of community* through interaction with women from the same ethnic background and same health condition. All the respondents stated the phrase “*We are family*” suggesting sense of belonging. All the positive sisters in the sample have disclosed their HIV status to at least one close person and 50 percent of the matches have not. For the matches that did not disclose their status to anyone at point of entry, the program provides them with a free nest to discuss issues surrounding the illness.

For the matches, the peer-match relationship provides a haven where they can freely express themselves with a fellow woman, unlike with the doctor they face cultural and religious barriers.

*“My boyfriend does not know about my HIV status, I do not have the courage to tell him yet. It is refreshing for me to discuss HIV issues with my positive sister, I feel I am not alone, I have a family. It is difficult for me to discuss certain issues with the doctor because of my religious beliefs”*

(M4)<sup>11</sup>.

Here the importance of interacting with the same gender, woman is emphasised especially by women with a Muslim and Christian background. For the positive sisters, they reveal that the program provides mutual help, they also feel a sense of belonging by supporting another woman. This is in line with the peer support concept provided by Dennis (2003), the positive sisters program lies within the direct effect model by providing participants with that sense of family.

However, this does not entail that the family is fully functional, without faults. When individuals from diverse backgrounds come together differences arise of different social norms and values held by these women. Trust and boundaries are of utmost importance when dealing with a sensitive issue such as HIV.

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<sup>11</sup> M4 is a match.

Both the peers and matches revealed that in the beginning of the match process they do not disclose much because they do not fully trust each other yet mainly due to social stigma.

### ***5.1.2. HIV literacy***

All the women in the sample revealed they gained more about HIV during by being involved in the program, indicating the importance of informal health care. It is however crucial to point out that lack of a control group to compare outcomes makes these findings suggestive.

*“I have learnt a lot about HIV transmission, medication and pregnancy by attending Positive Sisters activities, this is knowledge I did not have prior to joining” (PS 4)<sup>12</sup>.*

Most women’s knowledge on HIV is based on knowledge obtained in the home country which is usually small and at times false. Therefore, the PS program is very informational as most women indicate barriers to care within formal health care.

*“I go to my doctor’s visits but I am scared to ask questions because the appointment goes very quickly for me and I also do not speak very good Dutch and English” (M3)<sup>13</sup>.*

This statement from one of the respondents designates the language barriers that exist, creating a knowledge gap for these women. The activities and workshops planned by SHivA assist in bridging that gap. This knowledge gives them a deeper understanding of the disease and how to cope with it and helps retain them in care.

A crucial finding from more than 70% of the respondents is program fatigue. In as much as the women report increased knowledge from the activities and workshops provided by the program, they also report program fatigue. There is diminishing marginal utility derived from each extra activity because the activities are repetitive.

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<sup>12</sup> PS4 positive sister.

<sup>13</sup> M3 is a match.



*“I really enjoy going to the activities planned for the positive sisters and their matches but the activities are repeated, it’s the same workshops all the time. It is important to learn more information on HIV but I feel they do not fully understand us” (PS 5)<sup>14</sup>.*

On the messenger aspect, they imply that the activities are planned and conducted by people who might not relate to their concerns since they are not of African/Caribbean origin, not HIV positive and do not take HIV medication. Individuals are highly likely to embrace information if the messenger shares a similar background (Dolan et al 2012). Here the importance of role models is essential to influence behaviour change, peers who have been long in the program can be given a more significant role within the program. The program needs to address this finding because if some women stop attending program activities they might go back to their state prior to joining the program and drop out of HIV care completely because of loneliness.

### ***5.1.3. Empowerment***

The models of peer support state that peer support improves self-esteem through additional information, mediation and interaction with others (Dennis 2003). The improved self-esteem acts as a coping mechanism for the illness and women revisit their childhood dreams and goals leading to economic empowerment.

*“I thought my life was finished but interacting with other women made me realise I AM NOT HIV, I decided to pursue further education. (PS 2)<sup>15</sup>.*

This quote above suggests that when self-esteem is improved through peer support, focus shifts from the disease to economic empowerment or self enhancement. This is a significant finding because when women are not constantly thinking of the disease, they do not overweigh small probabilities and drop out of HIV care.

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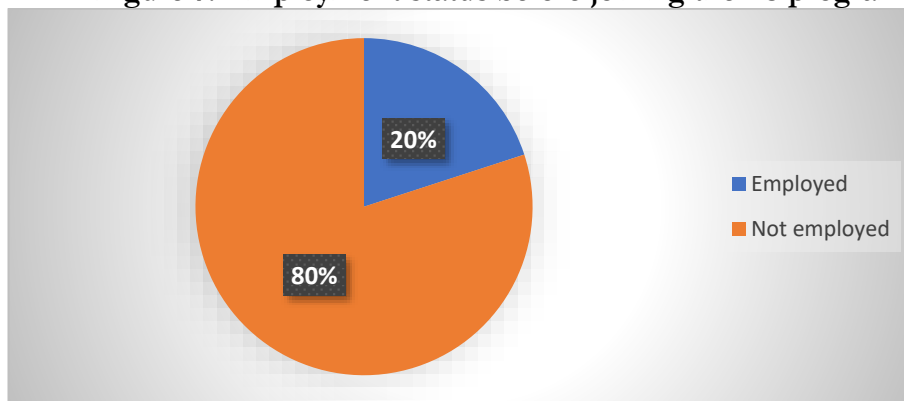
<sup>14</sup> PS5 is a positive sister.

<sup>15</sup> PS2 is a positive sister.

*The program director referred me to a coach who helped me decide what I wanted to study. He even helped me obtain financial funding for my studies” (PS 2).*

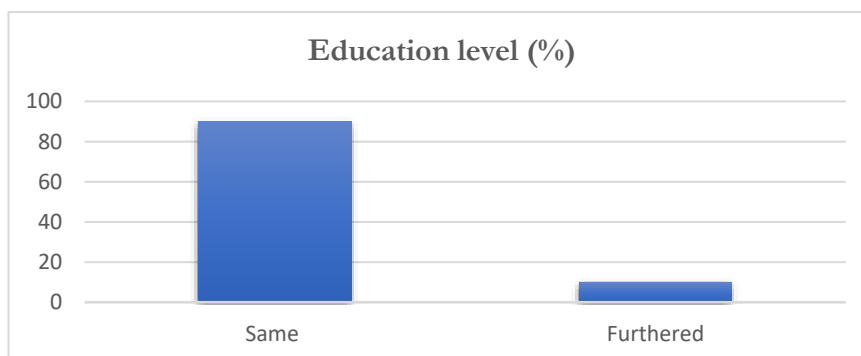
The program attempts to empower its participants economically, by encouraging them to further their education and seek employment. However more emphasis on this is required for those who can do so legally. Prior to the program 80% of the respondents were not employed and this includes those who are illegal migrants and 20 % were employed. After joining the program there is a slight increase in women who work part time and this includes informal jobs such as babysitting and house cleaning. This is illustrated in figure 7 below<sup>16</sup>.

**Figure 7: Employment status before joining the PS program**



*Source: Interview data (July, August, September 2017)*

**Figure 8: Education level before and after PS program**



*Source: Interview data (July, August, September 2017)*

<sup>16</sup> Figures reported in percentages based on a sample of 30 women.

Figure 8 above illustrates the education level of the respondents before and after joining the PS program. The level of education remained the same as before joining the program, only 10 percent of the women in the sample furthered their education. Some of the women in the sample are illegal migrants who are not allowed to work legally or pursue formal education. This might be the reason they are not economically empowered, not just because they do not want to or the program is not helping. The program should however provide this group with legal aid, to improve their legal status and provide them with activities so that they are not idle and focusing more on HIV.

#### **5.1.4. Mental health**

Mental health issues in this context refer to stress, anxiety and depression associated with HIV and other external stressors. Most of the women who had dropped out of treatment at a certain point, reported it was due to several factors with stress and anxiety being the leading factor. HIV diagnosis brings out many fears and ignites certain feelings that can lead to negative behaviour change.

*“I was ashamed of myself when I found out about my HIV status and I knew I was going to die anyway, so I stopped taking my medication and going to the doctor, I blamed myself for this disease”(M1)<sup>17</sup>.*

Most of the women who had dropped out of treatment at a certain point, reported it was due to several factors with stress and anxiety being the leading factor. Mental health issues in this paper refer to stress, anxiety and depression associated with HIV.

Models of peer support emphasise that peer support in health care leads to better psychological outcomes due to better coping mechanisms resulting from interaction, problem sharing and solving(Dennis 2003). This phenomenon has been evident in several studies and the findings from this research suggest that mental health is improved greatly during initial interaction. Respondents state

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<sup>17</sup> M1 is a match.

that the feeling of loneliness and self-blame is greatly reduced as they embark on the peer support journey. They however report that as they get stronger with coping with HIV and get less anxiety about it, there are other external factors that can affect their mental health status and potentially dropping out of HIV care. These factors include, legal status, housing situation and disclosure to partner and family and these stressors are in line with other studies. Arrey et al. (2016) yielded similar findings in their study on barriers to HIV care in Brussels, Belgium.

Although peer support programs in HIV care do lead to better mental health outcomes, they are short term due to other external factors affecting mental health not addressed by the program. Other factors that might constrain the effectiveness of peer support on mental health outcomes include the nature of the relationships between the positive sister and the match. Matching women with the same illness, with similar demographic backgrounds might not automatically result in improved outcomes.

This is because the women have their own individuality and personal traits developed from various social norms and values which influence the manner they interact with other individuals. Some people might be judgemental towards others or a click might just not exist and trust issues amongst matches might lead to undesired outcomes. Some individuals think more automatically and others are more reflective and this might impact peer match interaction.

People are social beings and are greatly influenced by their personal norms and values and those of the society and environment around them (Cialdini and Trost 1998). In the case of peer support the match and the peer will tend to influence each other either positively or negatively because of their interaction. The peer possesses her own set of norms and values concerning HIV and so does the match, therefore the interactions of these two individuals will have spill over of norms and values between the two women. The program should ensure that the peer match relationship yields positive behaviour change because people tend to be influenced by how other people behave.

The training program needs to dedicate more time on mental illness. 70 % of the Positive Sisters report that they need more tools on how to deal with a situation when they and their match have mental health problems.

*“I was very stressed because I received a negative decision from the immigration, I wanted time to myself to reflect on my situation. I told my positive sister about it but she kept calling and texting, I decided to block her number, I was overwhelmed I stopped my medication for 6 months and did not go to the doctor. I later resumed when my legal situation improved”*

(M6)<sup>18</sup>.

This statement from one of the matches reveals how more training is required on dealing with such complex issues. Peer support requires sufficient training that considers several behavioural factors to prevent positive sisters managing complex psychological problems inappropriately on their own.

### **5.1.5. Adherence to treatment**

Patient retention is heavily linked to adherence because HIV patients might be retained in care but not adhere effectively to medications. These two elements need to work together to ensure an effective ART regime because when an individual does not effectively adhere to medications it complicates one’s health (Stricker et al 2014). These 2 elements involve individual behaviours retention in care involves a patient’s participation in health visits and adherence involves a patient’s uptake of medication as prescribed. Ultimately if patients do not adhere properly to medication, it affects retention in care. This section will report the results on adherence, self-reported by the participants.

Adherence was measured by the frequency of medication intake, respondents were asked whether they take their medication daily, as prescribed by health care provider since joining the program. An in-depth interview then followed up to the answers providers to gain more insight on issues raised. The whole sample responded that they did not properly adhere to treatment since joining the program with reasons ranging from forgetting to simply not wanting. The

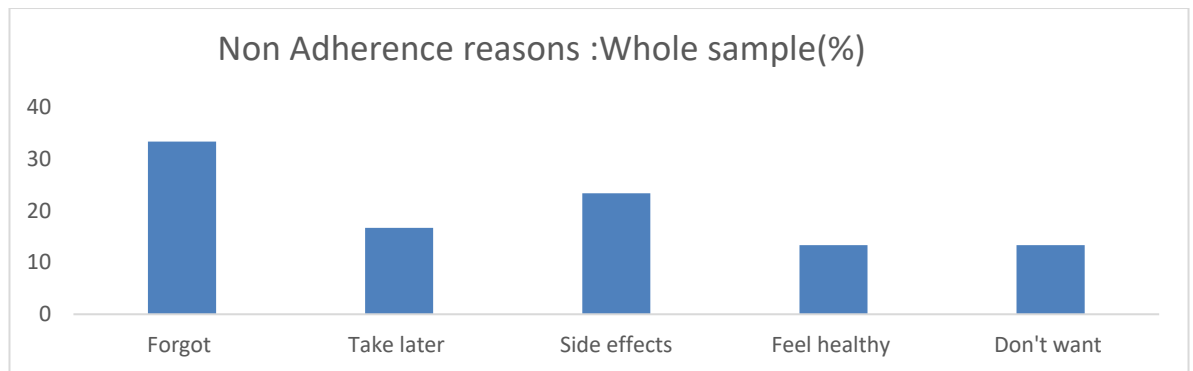
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<sup>18</sup> M6 is a match.

respondents cited individual reasons and not a combination of one or more reasons.

Figure 9 below gives an overview of the reasons given by the respondents for not adhering fully to medication, with 33 percent reporting they forgot and 23 percent citing side-effects due to medication.

**Figure 9: Reasons for non-adherence: Whole sample**

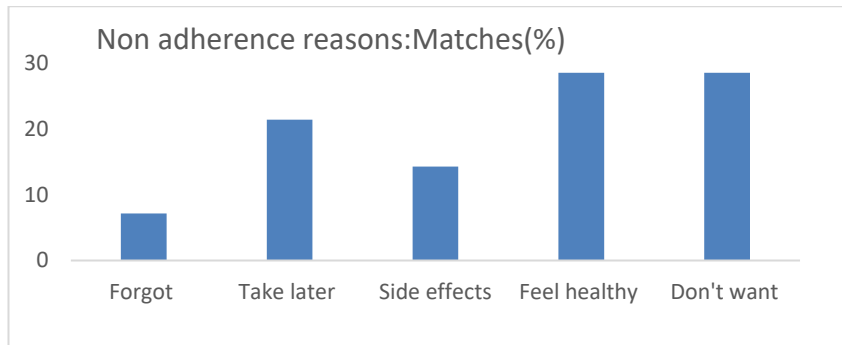


*Source: Interview data (July, August, September 2017)*

*“The medication makes me gain weight, making me less confident so sometimes I just do not want to take it” (PS2).*

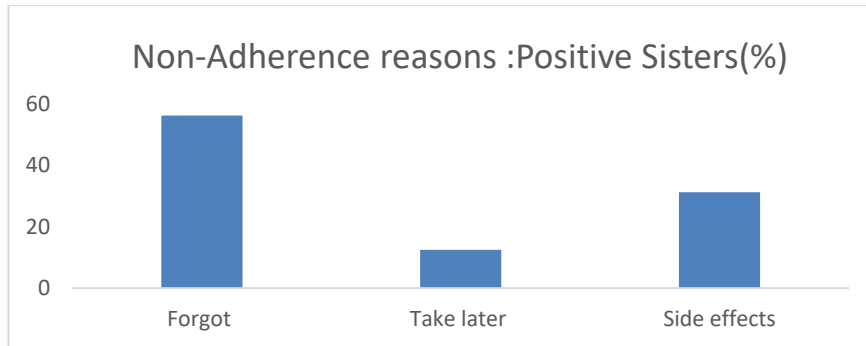
This statement is from a positive sister with University education, indicating that level of education does not matter when it comes to adhering effectively to treatment. It also discloses decision making under risky situations, she would rather prefer to stop medication and lose weight than gain weight and become healthy with the medication. This confirms how humans are not rational beings and can be affected by certain cognitive biases during the decision-making process (Kahneman 2011).

**Figure 10: Non-adherence reasons for matches**



*Source: Interview data (July, August, September)*

**Figure 11: Non-Adherence reasons for positive sisters**



*Source: Interview data (July, August, September 2017).*

Figure 10 and 11<sup>19</sup> above give an overview of non-adherence reasons cited by the respondents, distinguishing between the positive sisters who are the peer supports versus the matches who are being supported. The positive sisters cite 3 main reasons for non-adherence; forgot, take later and side-effects, with side-effects being the most cited reason. It is important to note that all positive sisters had non-adherence problems during the program showing no difference across demographic factors, such as age, marital status, religion, and level of education, employment status and residence status.

Several studies show that peer-support results in improved adherence, it would be expected that positive sisters, who are perceived to be emotionally strong would adhere properly to medication. This analysis shows how these decisions are driven by certain behavioural processes.

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<sup>19</sup> Figures reported in percentages based on a sample of 30 women.

Matches cited 5 reasons for non-adherence; forgot, take later, side-effects, feel healthy and don't want with the most cited reasons being feel healthy and don't want.

*“Why should I feed my body with medication when I do not feel sick, even the doctor's said I am healthy and my positive sister should not encourage me to take medication, when I am sick, I will take it”(M10)<sup>20</sup>.*

This finding reflects the lack of understanding of the working mechanism of HIV medication within the body. It also indicates that decision making in health care is on an individual level and peer-support might cause more harm than good for retention outcomes if not handled properly.

*“When I stopped taking my medication it was because, I knew I would eventually die of AIDS, so I decided to stop intoxicating my body with Western medication”(M2).*

Lack of trust in Western medication is also a key finding whereby women believe in traditional practices instead. For matches who cited feel healthy and don't want as reasons for non-adherence, they had legal residence problems and there were no significant differences across other demographic factors. Matches cite more reasons in comparison to positive sisters suggesting different cognitive biases that exist between the 2 groups.

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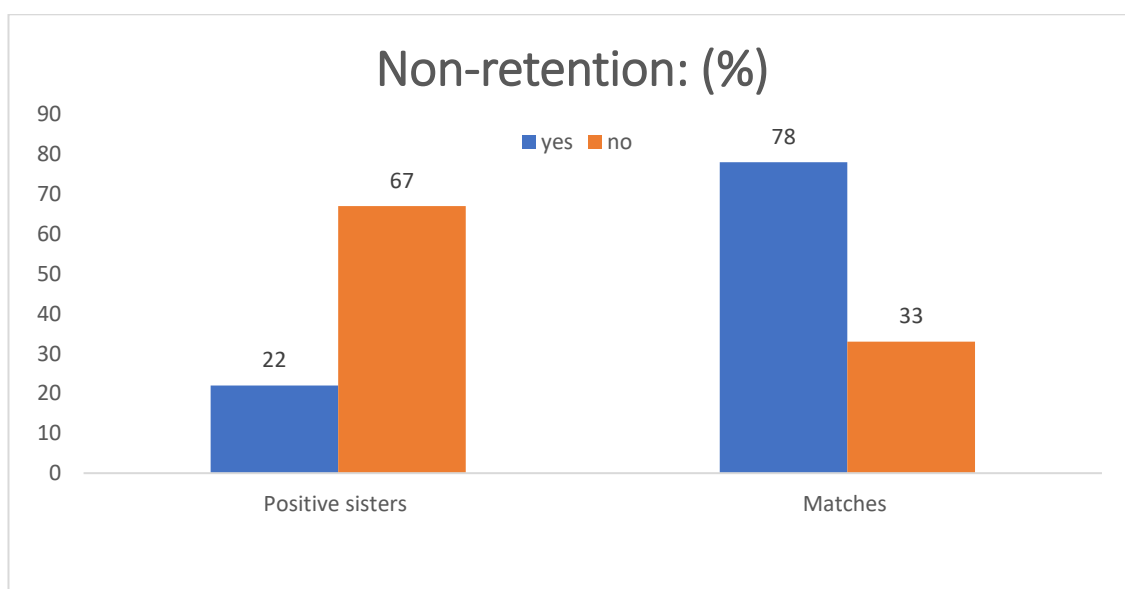
<sup>20</sup> M10 is a match.



### 5.1.6. Retention in HIV care

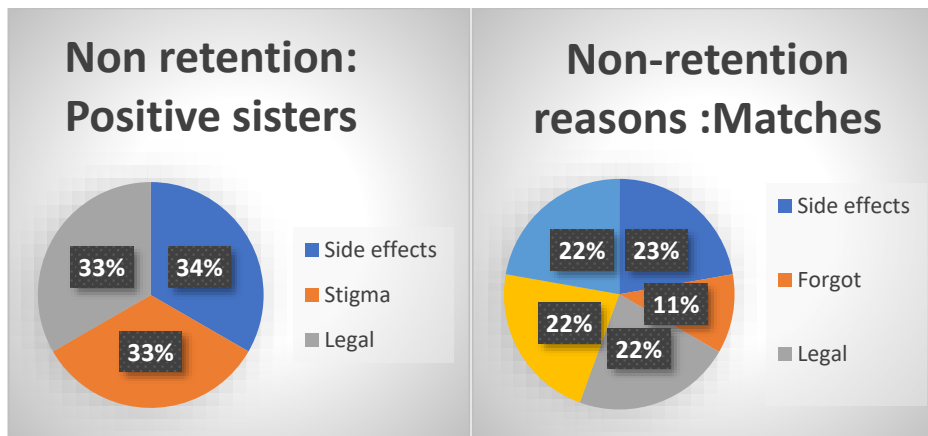
Retention in care is measured by the number of doctor's appointments missed since program entry and it is self-reported. The question asked to obtain these results was; have you missed any doctor's appointments since program entry? Figure 12 below shows the results of retention in HIV care across positive sisters and matches. Matches reported to have missed more doctor's appointments since joining the program, in comparison to positive sisters, 78 and 67 percent respectively.

**Figure 12: Non retention: Positive sisters and matches.**



*Source: Interview data (July, August, September 2017).*

Figure 13: Non-retention reasons, positive sisters and matches.



Source: Interview data (July, August, September 2017).

The charts<sup>21</sup> above shows an overview of the reasons given by the women in the sample for missing doctor’s appointments. The reasons include side effects, forgot, legal, stigma and did not want. Matches cite more reasons in comparison to positive sisters.

*“I did not go several times to the doctor because of the side effects from the medication, stress from my asylum procedure so after a while I just did not want to go anymore”*(PS 5).

This statement denotes that the women often have several problems that often become overwhelming, resulting in low retention in HIV care for the women. Although more focus for retention in care is on newly diagnosed patients, matches in this context, positive sisters need support as well.

*“When I received a negative decision from the immigration for my asylum procedure, I was scared to go to the hospital, I thought the police would be waiting there for me and I was not in any financial position to pay for hospital bills and medication, therefore I stopped going until my residence status improved”* (M1; M2; PS3; M5; M6; M8)<sup>22</sup>.

<sup>21</sup> Charts and figures are reported in percentages constructed from a sample of 30 women.

<sup>22</sup> A statement from various respondents, one positive sister and 5 matches.

The statement above from one positive sister was a common response from the women in the sample who cited they missed doctor's visits due to legal and residence status issues. Legal status in the Netherlands significantly affects retention in HIV care for the women. This is because for women without legal residence status and those in asylum seeking centres constantly live in fear and the stress associated with the situation also stops them from going to the doctor. Across all demographic and individual characteristics residence /legal status in the Netherlands significantly affects HIV care retention.

The goal of the peer support program is to empower women to accept their HIV status and move ahead with their life and residence matters are beyond the scope of the program. However respondents from the sample state that the program tries to a certain extent to assist program participants with residency problems.

*"The program director referred me to a well-known immigration lawyer when I was faced with deportation and it turned my situation around"*

(M9).

This indicates that awareness exists within the SHivA organisation structure that residency issues affect retention and the program tries to address it within its capacity. However more can be done for this group since it is associated with stress, fear and anxiety leading to less retention.

This section has reported the results from the sample and there is a clear picture from the participants' perspective that the program does aid in retaining its participants in HIV care. However, this is not an automatic process, program entry and participation does not directly result in HIV retention. There is a pathway illustrated in figure through which the positive sisters program achieve retention. The pathway starts from social belonging, increased HIV literacy, empowerment (self, economic), improved mental health, better adherence to increased retention in HIV care. The results from the sample of women, will be compared to the results of the key informants in the following section. This is to find out whether a gap exists between participants and key informants views to retention in care.

## **5.2. Key informants' results**

This section will report the results from the key informants which include, a representative of the HIV team from Westeinde hospital in The Hague and a key informant from SHivA.

### **5.2.1. HIV team (HMC Westeinde hospital, The Hague)**

The HIV team at HMC Westeinde hospital in The Hague was interviewed and this hospital was chosen because most women from the sample go to or have gone to this hospital. Other reasons include quick response from the team and close vicinity to researcher's place of residence. The goal of the interview was to gain insight into the adherence and retention behaviours of the women in the sample who are treated at this hospital.

However, the team could not provide me with exact figures concerning frequency of visits and prescription renewal due to confidentiality and ethical reasons. They did provide a general outlook on adherence behaviours of sub-Saharan African and Caribbean women and participants of the positive sisters program they treat.

The team indicated that although some women are not retained in care, by missing doctor's visits retention in care within this focus group is not a major problem within their hospital. The hospital organises various activities targeted towards this focus group, such as annual HIV positive women days, emoji reminders and alliance with the positive sisters program. There is also a social worker within their team because they noticed that women often have a lot of other problems on top of their chronic illness. The integration of such activities and the presence of a social worker into their existing structure is a major contributor to retaining more women in care.

With regards to the positive sisters program the results from the team suggest that it contributes greatly to improved adherence and retention by bridging the cultural gaps that exist between health professionals and the women.

*“Women often come here with a lot of other problems and sometimes without any outlook on life, no hope for the future. As a nurse I try my best to encourage them but when I see the first interaction of a match with a positive sister, the reaction and communication from the match is unbelievable. Most times the match is shocked to see a healthy-looking woman, confident woman telling her she is also HIV positive” (HIV nurse<sup>23</sup>).*

The statement indicates how the positive sisters program is perceived within their team and how peer support can influence a patient in a manner a specialised health professional cannot. According to the HIV team, the positive sisters program provides women with a sense of community, recognition and support beyond formal health care structures.

*“The women relate better with other women from the same country of origin, cultural and religious background. There are certain issues they feel comfortable discussing with another woman of similar background than they would with me” (HIV nurse).*

Health professionals appreciate the need for extra support beyond formal health care for this focus group to influence behaviour change towards better adherence and retention.

**Table 1: Reasons for non-adherence and non-retention**

Religion	Stigma	Distrust in Western medicine	Mental illness	Partner Influence	Residence /Legal status
<ul style="list-style-type: none"> <li>• God heals</li> <li>• Doctor visits but no medication intake</li> </ul>	<ul style="list-style-type: none"> <li>• Self</li> <li>• Social</li> <li>• Health professionals</li> </ul>	<ul style="list-style-type: none"> <li>• Belief in herbal medicines</li> </ul>	<ul style="list-style-type: none"> <li>• Stress</li> <li>• Anxiety</li> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Submission to partner (cultural and religion)</li> </ul>	<ul style="list-style-type: none"> <li>• Fear of being caught</li> </ul>

*Source: Interview data (October 2017).*

Table 1 above shows an overview of the reasons for not adhering well to medication and missing doctor’s appointments, from the perspective of health care professionals, the HIV team. Six reasons are cited; religious beliefs, stigma,

<sup>23</sup> HIV nurse is part of an HIV specialized team at the HMC Westeinde Hospital in The Hague.

mental illness, partner influence and residence status. These reasons are in general for women from sub-Saharan Africa and the Caribbean including participants of the positive sisters' program. An interesting finding is that health professionals cite some reasons that were not cited by the positive sisters and matches, these include religious beliefs, lack of trust in Western medication and partner influence.

Stigma is cited as the major barrier to proper adherence and retention, self-stigma that stems from self-blame and shame, contaminating the body.

*“Some women come to me and say there is no reason to take medication because they are going to ultimately die from the disease they brought upon themselves, therefore they stop with doctor visits as well until they fall seriously ill”*(HIV nurse).

The statement reveals a psychological issue and lack of HIV literacy .The nurse stated:

*“HIV is related to sex since it is mostly sexually transmitted, creating negative perceptions especially for women living with HIV .Some patients stop coming to the hospital because they do not want to be seen by the people they know in the HIV waiting room”*(HIV nurse).

Social stigma from the community at large also acts as a barrier resulting in women disclosing their HIV status to close family and friends and sometimes even their partners Health professionals revealed that sometimes women do not come back to doctors' appointments because of stigma from stemming from doctors and nurses.

*“A woman was coming from another specialist within the hospital to the HIV specialist and on the form from the specialist, it was written in bold red marker HIV positive. The woman did not come back to the hospital but we as a team we advised that department to never do that again”*  
(HIV nurse).

Stigma from health professionals can be overwhelming for patients with HIV resulting in dropout from treatment and HIV care (Carr and Gramlin 2004). Most women living with HIV have some sort of religious belief, with many following either Christianity or Islam beliefs.

*“I have had patients who tell me they are not taking medication anymore because they have prayed to God and have asked for God’s healing. Some women stop with medication intake but still visit the hospital and after a while fall very ill and start medication again. Some women have even gone to seek prophetic healing from some famous African religious figures”*  
(HIV nurse).

This indicates how religion plays a significant role in influencing behaviour and peers and matches can influence each other towards such beliefs. Religious belief is on an individual level but it is costly to the individual and the health professionals when women do not adhere and dropout of care completely. Health professionals suggest that more outreach in the community, religious leaders, at churches and mosques is needed to spread awareness on HIV and the dangers of stopping medication intake. (Maman et al 2009, Zou et al 2009, Parsons et al 2006).

Another reason given for poor adherence and low retention in care for this focus group is lack of trust in Western medication.

*“Sometimes when women travel to their country of origin in Africa, they often do not come back to the hospital, and when they do, they reveal they went to a traditional herbalist in their country of origin because they did not believe Western medication works for Africans and dark-skinned people”* (HIV nurse).

This indicates how cultural practices influence health outcomes and distrust in Western health care practices is common among HIV patients with an African origin (Erwin and Peters 1999).

Partner influence is another reason for non-adherence and non-retention probably because the partner lacks knowledge on the importance of consistent adherence and retention.

*“Partners talk women into stopping medication intake because they look healthy and for religious reasons. Due to cultural factors, women submit and listen to their partners until they develop medical complications”* (HIV nurse).

Women have peer support within the positive sisters' program but at home there is another voice speaking resulting in the woman dropping out of the positive sisters' program and HIV treatment. This is where peer support for partners is essential to achieve desired health outcomes (Montgomery et al 2011).

The HIV team revealed that under Dutch law, patients with a chronic illness such as HIV are entitled to health care access despite their residence status. Patients need to discuss their situation with the social worker and for medication it is subsidised for patients who cannot afford or access a health insurance. In this case they need to pay 5 euros per medication. However, 5 euros per medication might not be affordable for some patients, therefore they buy the medication whenever they can afford it, resulting in medication resistance and health complications for some.

Although these results are a reflection of women from one hospital, they do give an indication of the perspectives from health care professionals.

### ***5.2.2. SHivA key informant results***

A key informant from SHivA was interviewed to understand why the support program was set up for this focus group and the reasons for poor adherence and non-retention from their perspective and how the program addresses it. The positive Sisters program was created for informational support, contact with similar women and for empowering women to reach their full potential despite having HIV.

*“The program was created solely focused on sub-Saharan African and Caribbean females because this group is the most affected with HIV and most vulnerable also”* (SHivA key informant).



**Table 2: Reasons for non-adherence and non-retention: SHivA**

Religion	Stigma	Lack of trust	Mental illness	Suicidal feeling	Multiple problems	Messenger and Framing
<ul style="list-style-type: none"> <li>• Spiritual healing</li> </ul>	<ul style="list-style-type: none"> <li>• Self</li> <li>• Disclosure</li> </ul>	<ul style="list-style-type: none"> <li>• Distrust Western medicine</li> <li>• HIV does not work for black people</li> </ul>	<ul style="list-style-type: none"> <li>• Guilt</li> <li>• Blame</li> <li>• Shame</li> <li>• HIV and the body</li> </ul>	<ul style="list-style-type: none"> <li>• Fear</li> <li>• No future outlook</li> </ul>	<ul style="list-style-type: none"> <li>• Problems such as residence status</li> <li>• Financial problems</li> </ul>	<ul style="list-style-type: none"> <li>• Health professionals as authority</li> </ul>

Source: Interview data (October 2017).

Table 2 above shows an overview of non-adherence and non-retention reasons for positive sisters and matches from the perspective of SHIVA. Reasons such as religious beliefs, distrust in Western medicine, mental illness and stigma are in line with the reasons given by the HIV team from the hospital. However, the key informant cited some reasons for non-adherence and non-retention that were not mentioned by the program participants and the HIV team. These reasons include; suicidal feeling, multi problem situations, messenger and framing. These reasons will be elaborated in more detail below.

Some women have stopped HIV treatment due to suicidal feelings which stem from the fear and confrontation with HIV.

*“Some women are extremely afraid when they find out they are HIV positive, they lack a positive outlook on life. In their minds they think why take medication when I will die of AIDS”*(SHivA key informant).

This statement indicates distress but also a lack of proper HIV literacy because the death from AIDS is not quick but there is a slow progression which is more painful and stressful. In this case peer support is useful because it provides informational support which can assist the woman to shift her outlook on life towards positivity.

SHIVA is aware that this group of women often harbours several other problems on top of dealing with HIV, “multi-problem situations” according to the key informant. The problems range from financial, personal (partner, children), transport costs to legal. Women without legal residence status and those in asylum seeking centres often do not have enough financial resources.

*“Some women have to take the train to travel to their treatment hospital and it’s costly for some ,therefore if a woman can not afford it at that time ,she will not go ,she will only go when she affords”(SHivA key informant).*

This statement reflects how certain problems such as transportation costs do not only occur in the developing world ,but also in the developed world.These problems coupled with the burden of dealing with HIV often lead to women stopping HIV treatment (Hodgson et al 2014). The key informant mentioned that SHivA works with other organisations that provide financial and legal support to HIV positive migrant women.However there needs to be coherent communication between SHivA ,positive sisters and matches because some participants are oblivious that such structures exist for them.

A key result from the key infromant from SHivA concerning non-adherence and non-retention of program particiapants is the messenger and framing of information by doctor’s and nurses.

*“ The doctor is viewed as higher authority and there is often not much time between doctor and patient.Sometimes the women cannot relate with the manner in which the doctor interacts with them due to different cultural backgrounds between doctor and patient”(SHivA key informant).*

The positive sisters program tries to bridge this gap by matching women from similar regions of origin and provide informational support.

*“Matches between women women from the same region of origin work best for example a positive sister from East Africa will have a good experience supporting another woman from East Africa”(SHivA key informant).*

This suggests that participants benefit more from interacting with a fellow woman because the cultural barriers are broken.

Self stigma was mentioned as the major reason for non-adherence and non-retention whisch stems from blame and shame.

*“Because HIV is linked to sex and the body from transmission of HIV to oral intake of medication ,women often blame themselves for contaminating the body with HIV,it becomes a mental issue”*(SHivA key informant).

This shows the delicate need for professional psychological advice because this individual mental process can be beyond the scope of positive sister. This also reveals that SHivA is aware of the behavioural processes that affect decision making towards adherence and retention behaviours.

This section covered the findings from the positive sisters matches and key informants.From both the perspective of the PS participants and the HIV team ,the PS program does help retain women in HIV care.The social belonging and empowerment through enhancing self-esteem are cited as the strong channels through which the program retains women in HIV care.Most reasons for non-adherence and non retention given by the PS participants are in line with the reasons given by the key informants.This signals that these key informants are aware of the barriers to treatment and care that exist for this focus group.Key informants are also aware that certain behavioral processes govern the decision making of the women.

However there is a knowledge gap that exists between program participants and key informants.For instance the HIV team is aware that illegal migrants can access HIV care and treatment through the assistance of a social worker but the key informant from SHivA is not aware of it.

### **5.3. Behavioural process towards adherence and retention in HIV care**

The findings from section 5.1 and 5.2 above suggest that there are cognitive biases that drive the decision-making process of the women in the sample as reflected by their reasons for non-adherence. This section will analyse the biases that drive the reasons given across positive sisters and matches. The cognitive

biases that explain the reasons given will be limited to self-control, time-inconsistency, mental models, and risk. Cognitive biases refer to the systematic error in thinking that affects the decisions and judgments that people make, often influenced by various norms, values and experiences. It is however important to note that the findings in this section are based on indicative evidence. Actual field experiments would be required to gain more substantiation and verification on the cognitive biases that exist within this sample.

They are viewed as a deviation from economic man, from rationality, in this context the rational decision would be to adhere properly to medication and continue with HIV treatment. Three cognitive biases have been identified in this study; self-control, time inconsistency and mental models. These biases have been extracted from the reasons given by the positive sisters and matches for non-adherence and non-retention to HIV treatment.

**Table 3: Behavioural processes towards adherence and retention decision making**

Self Control	Time inconsistency	Mental models
<ul style="list-style-type: none"> <li>• <b>Forgot</b></li> <li>• <b>I do not want</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Side effects</b></li> <li>• <b>Take later</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Feeling healthy</b></li> <li>• <b>Stigma</b></li> </ul>

*Source: Interview data (July, August, September, 2017).*

Table 3 above shows an overview of the cognitive biases derived from the findings, the subsequent section will give detailed explanation of each cognitive bias.

### **5.3.1. Self-Control**

Self-control depicts a commitment problem, the women in the program commit to medication intake and hospital visits but somehow, they do not stick to the commitment. This is the “*present bias*” phenomena, whereby individuals initially commit to something but default from the initial plan (Laibson and List 2015:387). Forgetting medication intake depicts this problem of self-control

and all the women in the sample have self-control problems when it comes to medication intake. In this context, the women are faced with 2 choices, to adhere fully to medication or not, knowing fully the consequences of both choices.

The “*choice architecture*” which refers to the manner in which a choice is structured for an individual to make a decision (Thaler and Sunstein 2008:357). The women receive information on the importance of correct daily medication intake, meaning proper adherence now will guarantee long-term health benefits. This would represent rational behaviour but the women are not applying self-control leading to under valuation of the future health benefits from proper and correct adherence.

The self-control bias is driven by an overreaction to new information especially for newly diagnosed matched, they become overwhelmed combined with poor HIV literacy. The choices made are driven by various norms and values and can affect the decision making of peers. For example, if a positive sister tells her match that she regularly forgets to take her medication on time but she still is healthy. The match might think this is acceptable behaviour and adopt the same strategy as well, forgetting that individuals have different immune systems and health complications. The match might end up not taking her medication at all and not going to her doctor’s visits.

Positive sisters, health professionals and the director of the program are the messengers in this case. Depending on how all these messengers convey information to the participants, their decision making is also affected. The program deals with this bias during the training process by teaching positive sisters not to give advice. Most of this self-control problems are on an individual level such as religious beliefs and the program emphasises the importance of medication intake considering various religious beliefs.

### ***5.3.2. Time-inconsistency***

Reasons such as side effects and deciding to take later reflect a “now or later” decision making process because an individual is busy or not feeling well at

time of consumption indicate time-inconsistency bias (O'Donoghue and Rabin 1999:103). These decision-making processes reflect lack of thorough understanding of the consequences of poor medication adherence.

### ***5.3.3. Mental models***

Human beings apply mental models and various frames when dealing with a certain situation for example some HIV patients regard HIV and AIDS to be the same based on previous education and lack of proper information. During the decision-making process, people tend to assign great weight to small probabilities (Kahneman and Tversky 1979). For example, some women revealed they do not go to the hospital because they fear seeing someone they know in the HIV waiting room, this is a form of self-stigma. Stopping HIV treatment because one feels healthy indicates that they rely on previous knowledge of HIV, that if one has HIV one has to be ill and frail. Religion also influences this decision because if a woman believes God is healing them, they do not take medication.

In this case basic HIV knowledge will be irrelevant, peer educators need to gain a deeper understanding of what mental models people possess and what drives them through improved training. The way people think is driven by societal norms and values, and life experiences and these differ per individual. Various mental models are positive whilst some are negative and may sometimes be conflicting hence policies need to trigger positive mental models to create greater benefits.

These cognitive biases suggest that participants need more education on the importance of proper adherence and doctor visits. Although the program attempts to address this through informational workshops, decision making is also driven by contextual factors beyond the programs' scope and the individuals' willingness to adhere and go to the doctor.

## 5.4. Strengths, Weaknesses, Opportunities and Threats (SWOT) of PS program

Figure 14: SWOT Analysis of PS program



Source: Interview data (July, August, September, October 2017).

The figure above displays a SWOT analysis of the PS program based on the results from positive sisters, matches and key informants.

**Strengths:** The PS program creates a sense of belonging for participants, improves self-esteem, HIV literacy leading to improved outcomes on adherence and retention in HIV care. There is a valuable feedback communication between SHivA and hospitals and improved HIV literacy demonstrates the importance of informal health care systems, peer support in this context. Program addresses certain cognitive biases during program training. In addition the PS program understands the importance of early commencement of ART by supporting newly diagnosed women.

**Weaknesses:** Diminishing marginal utility of program consumption due to repetitive programs and workshops, poses a threat to retention in care. Therefore program goals should be tailored to match participants' needs. The program

does not have a quantitative database with demographic information of participants.

**Opportunities:** The PS can serve as an informal health care success story if combined with other strategies such as integration of organisations that address barriers to care such as legal and financial into the training program, workshops and activities. It also has an opportunity to be integrated into health insurance schemes, creating incentives for peers and lessening the financial burden on the program.

**Threats:** Short-term funding acts a barrier to the scaling up of the project.

**Figure 15: Feedback mechanism between the PS program, informal, formal healthcare providers and research**



*Source: Interview data (July, August, September, October 2017).*

The figure above gives an illustration of the link between the PS program with formal health care, various informal organisations and professional support. The positive sisters program helps retain women in HIV care, creating awareness in the professional and research world. The PS program receives free evaluations and research from various professional organisations, emphasising on the importance of peer support on disadvantaged groups in health care access.

*“SHivA provides willing positive sisters to other organisations and projects for example the Diversity and culture video projects by SOA AIDS Netherlands showing the journeys of various women. These videos are being shown in various hospitals to empower other women and men living with*



*HIV. Some of our matches were encouraged to participate by these videos”*  
(SHivA key informant).

This shows how the PS program interaction with other organisations retains more individuals in care, women and men included.

## Chapter 6 : Discussion and Limitations

### 6.1. Discussion

The results reported in prior sections suggest that the PS program does facilitate retention of participants in HIV care through the defining elements of peer support according to Dennis (2003). The mechanism in which the PS program achieves this result is not direct, program entry does not result in automatic and guaranteed retention, there is a process towards retention illustrated in figure 6. Various elements within this process are essential for optimal outcomes and several external factors can affect these elements resulting in lower retention outcomes.

The PS program matches women based on similar backgrounds, in accordance with the concept of peer support (Dennis 2003). The key informant from SHivA reported that the best matches stem from matching women from the same region of origin. This strategy comes with certain trade-offs and downsides. The trade-offs result from the initial sense of belonging when the matches feel comfortable relating with other women from the same country. However as the match relationship progresses, downsides might occur due to personality clashes. Personalities might matter more in developing a good relationship that yield positive health outcomes (Ajzen 2005). Expanding the program to matching women of different ethnic backgrounds might yield better outcomes but still that initial sense of belonging is a crucial foundation.

The PS program does help retain women in care through sense of belonging, improved HIV literacy and self-empowerment, the benefits seem to be short-term. This result is in line with other studies that advocate for the need of peer support in health care because it results in better and improved health outcomes (Bezabhe et al 2014, Govindasamy et al 2014, Deering et al 2009). However there is a question of short-term benefits vs long term sustainability of the program because of program fatigue reported by the respondents. Simoni

et al (2009) indicate similar findings of short-term health benefits of peer support. To sustain benefits in the long-term, the program might have to be combined with other strategies.

Matches report to have missed more doctors' visits than positive sisters, the findings illustrate that both groups of women occasionally suffer with poor adherence to treatment and low care retention. This could be explained by external problems and cognitive biases. Even though positive sisters are expected to be stronger or rather *rational*, they still suffer from the same shortcomings that matches have. This further illustrates that cognitive biases can influence all individuals even those who are expected to be stronger in certain situations (Kahneman 2011). This evidence is rather suggestive, evidence from actual experiments would be needed to solidify findings.

At a certain point during the program, the participants start experiencing diminishing marginal utility to program support and activities. The danger of this is that participants might end up dropping out the PS program. Consequently, they might end up dropping out of HIV care as well especially when faced with extreme problems due to the lack of the initial support and social belongingness. Although the respondents report program fatigue they continue attending program activities. Therefore, the program fatigue could be due to external factors such as financial and legal problems or as a result of cognitive biases. However, the key informant from SHivA was told about this finding and suggested SHivA would introduce new activities for keen participants but lack of sufficient funds acts a barrier to this.

Individuals tend to make decisions based on memory not experience. Just because the activities and workshops are boring, it doesn't indicate that the whole experience was boring, but people attach more value on the last memory (Kahneman 2011). During program entry, women have a lot of energy and are excited to interact with women in the same situation. As the program progresses and they gain more knowledge, feel a sense of belonging and get empowered. Gradually the excitement declines, they yearn for growth beyond improved self-esteem, but activities become monotonous, they want to stop

attending. They attach great weight to the recent memories of the program, which are bad for them, but it does not imply that the entire experience has been bad (Kahneman 2011).

Concerning mental health, the PS program is aware that behaviours towards retention and adherence are driven by external factors such as legal and financial problems that result in stress, depression and anxiety. Women with HIV are more prone to psychological problems that stem from HIV and other factors (Dodds et al 2003, Reece et al 2003). Patient retention is a challenge for participants who have residence or legal status problems. The program demonstrates dedication to its participants by moving out of its scope of focus to address external factors that influence adherence and patient retention. For instance, participants with financial and legal problems are referred to organisations that can assist them.

Additionally, SHivA can educate the women about the existence of these organisations so that participants can contact themselves in case of need. This is because not everyone is open to discuss their problems with a peer supporter, serving as privacy to the woman and retaining more women in treatment through less burden of external problems. The National Health Care Institute of the Netherlands subsidises health care costs for illegal migrants. This information needs to be communicated during training because the PS will be the point of contact for a match and needs to know and relay this information when needed. Although this helps retain women in care, women without a legal residence status might still be fearful of going to health care centres because of fear of being deported if caught. Another barrier is the cost, 5 euros per medication every month, might seem reasonable but might not be affordable to some. The organisation could identify women who require financial assistance regarding medication consumption.

Program training includes an intensive six days of training and a weekend away, on one of the training days, a psychologist is present to give psychological training. The emphasis should be on quality and follow up of training vs number of training days. Follow up training days are required because the positive

sisters are not trained professionals and the notion of not giving advice to their match could be difficult. Positive sisters always need to keep in mind to listen carefully and not give advice each time they talk to their match resulting in an unnatural flow of the conversation.

Availability of a program alone does not ensure health outcomes such as retention in care and adherence will be successful. Other factors need to be considered for the intervention to be successful. An intervention needs to be accepted by the participants, there needs to be a coherent communication from the leaders to the participants (Deering et al 2009).

## 6.2. Limitations

Program entry is voluntary, women choose to participate or not and this generates *self-selection bias*. The sample of respondents is not random, it is self-selective. This results in an imprecise representation of the “population distribution of characteristics” that does not precisely define the correct population despite how large the sample size is (Heckman 1990:201). Women who choose to participate in the PS program might be able and willing to achieve better health outcomes for themselves. Reasons to join the program are not driven by any financial incentives since positive sisters are paid a volunteer fee of 120 euros annually. Hence, willingness to join the program reflects that these women possess a high likelihood of achieving positive outcomes. Hence the results of the study can not only be attributed to the program itself but also to the participants.

In addition, lack of a *control group* inhibits the attribution of the findings solely to the program. Comparison of outcomes of women who do not participate in the program would enable assignment of impact of outcomes to the PS program. However, the study only explores participants of the PS program. If there was a control group and outcomes were different, the results would be attributed to the strength of program. Program participants might possess unobserved elements which the control group may lack, such as willingness or

ability. In this context it is difficult to assess the exact impact of the program on adherence and retention outcomes.

Furthermore, the cognitive biases identified in this study are based on suggestive evidence. Actual *behavioural experiments* would be required to determine the actual cognitive biases that influence the decision making process of the women towards adherence and retention outcomes.

The qualitative data used for retention and adherence outcomes is *self-reported* which creates a bias. It would have been beneficial to make a comparison between self-reported outcomes and actual recorded outcomes but there was no access to recorded data.

### **6.3. Future Research**

Various research can be undertaken from the underlying findings of this study. Research on the effectiveness of the PS program can be implemented using a treatment and control group. The findings from this study suggest that the PS programs aids in retaining women in HIV care, it would be useful to conduct research on the cost-effectiveness of the PS program. Research involving actual field or lab experiments can be implemented to pinpoint the actual cognitive biases that affect decision making in HIV treatment and care.

## Chapter 7 : Recommendations and Conclusion

### 7.1. Recommendations

The findings from the research indicate that the PS program does help retain participants in HIV care, assists with adherence to treatment, addresses mental health issues to a certain extent and is familiar with some behavioural process that influence decision making towards retention in care and adherence. The program can however be improved to yield even better outcomes and be scaled up. This section will focus on recommendations that could assist in scaling up the program.

Gain framing vs loss framing helps in changing and inducing behaviours (Kahneman 2011). Gain framing vs loss framing can guide policies and interventions into changing behaviours towards desired outcomes. For example, the statements below can be used and emphasised more during the training sessions of positive sisters.

***Daily medication intake improves your health***

***If you drop out of treatment you will eventually die***

Commitment devices are mechanisms that can be used by interventions to achieve desired program outcomes (Brocas et al 2014). For example, the program could incentives such as day trips or weekends if only the women attend all their doctor's visits and adhere properly to treatment. Hence the program needs to introduce new activities that run along with the existing program activities, for example organise weekends for women twice a year, (Vyavaharkar et al 2007).

Women should be encouraged to be more in control of their health by asking questions concerning their health when they visit the hospital or during PS program activities. The National Health Service (NHS) of England launched a 3 questions campaign in 2016 whereby patients need to ask 3 crucial questions about their health during a doctor's appointment (National Health Service

2017). This campaign can be used as a point of reference to encourage women to ask questions concerning their health.

There should be an interaction between participant needs and program goals. People tend to feel more accomplished when doing something relevant that helps other individuals, their ego is boosted. Positive sisters should be given a more significant role rather than just volunteers. Most of these women have no relatives in the Netherlands and consider the positive sisters to be family, hence social support beyond health outcomes needs to be granted because it certainly affects relevant health outcomes. Positive sisters should be provided with a more significant role.

## **7.2. Conclusion**

The research objective was to investigate whether the positive sisters program helps retain participants in HIV care. The findings indicate that the program does assist retain women in care through informational, mediating and appraisal support. In addition, it facilitates with mental health issues and is aware of some of the behavioural processes towards decision making in HIV retention. However, these findings are only suggestive because there is no comparison of outcomes of women who were not offered the program therefore outcomes cannot be solely attributed to the program. Moreover, emphasis on the training of positive sisters is required since they are not professional psychologists but support women with multi problem situations. Although financial funding for the program is an immense obstacle for the scaling up of the program, focusing on the essential needs of the current participants is crucial. The program does however serve as a benchmark of how formal and informal healthcare systems can be integrated to achieve optimal outcomes in HIV care.



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# Appendices

## Appendix 1: Map of HIV specialized hospitals in the Netherlands.

Map 1: Map of the Netherlands showing HIV specialised health centres

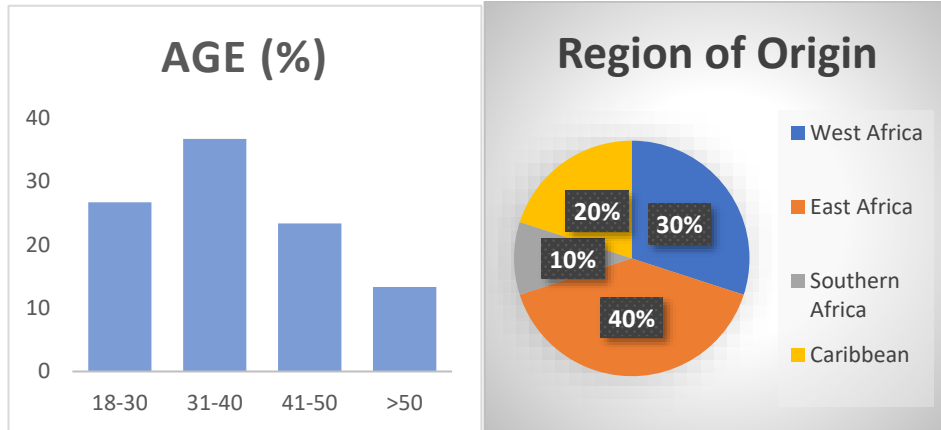


Source: (Stichting HIV Monitoring 2017)

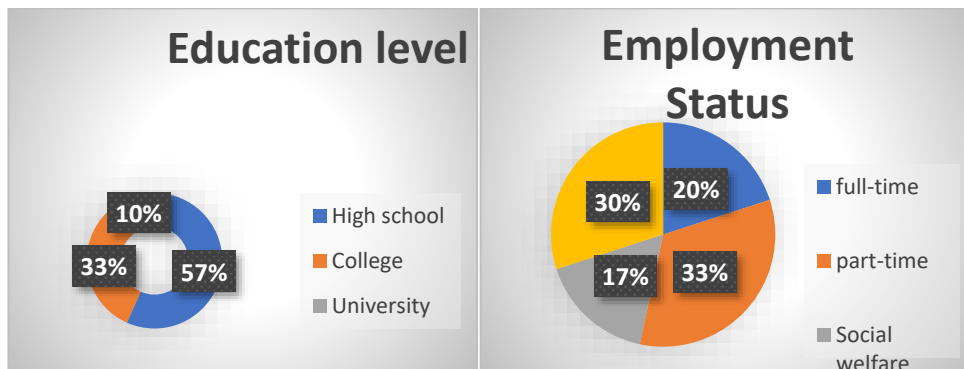


**Appendix 2: Descriptive Statistics of respondents (positive sisters and matches)**

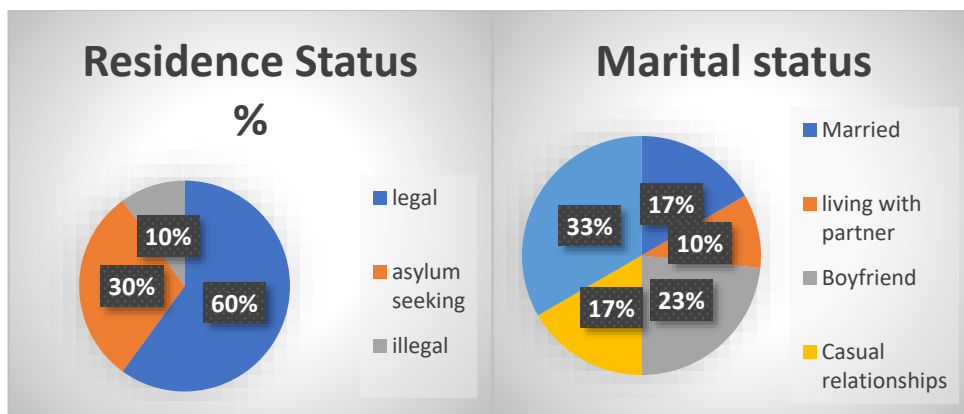
**Figure 16: Age and region of origin of respondents**



**Figure 17: Education and employment status of respondents**



**Figure 18: Residence and marital status of respondents**



### **Appendix 3: Informed consent form for participants**

#### **Research Information**

**Principal Investigator:** Amanda Mariga

**University:** Institute of Social Studies, Erasmus University.

**Research Topic:** Peer support and retention in HIV care

This Informed Consent Form has two parts:

1. Information Sheet (to share information about the study with you)
2. Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed consent form

#### **Part I – Information Sheet**

I am Amanda Mariga, studying at the Institute of Social Studies, Erasmus University, The Netherlands. I am doing a research on the Positive Sisters project of SHivA, looking at its benefits on retention, adherence, and mental health of its participants. I am going to give you information and invite you to be part of this research. You do not have to decide today whether you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, please do not hesitate to ask me.

This research will involve your participation in an individual interview that will take about one hour.

You are being invited to take part in this research because we feel that your experience as Positive Sister or match or key informant can contribute more insight on the effectiveness of the PS program on the outcomes mentioned above.

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate, all the services you receive in this program will continue and nothing will change.

#### **Procedures**

- A. I am inviting you to take part in this research project. If you accept, you will be asked to provide some information concerning the positive sisters program, related to barriers in HIV care, adherence and retention in care.

- B. You will participate in an interview with myself. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information that you will provide is confidential, and no one else except me will have access to the information documented during your interview.

### **Risks**

I am asking you to share some very confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give me any reason for not responding to any question, or for refusing to take part in the interview.

### **Benefits**

There will be no direct benefit to you, but your participation will help me understand more about the benefits of the Positive Sisters project and to potentially scale it up by helping more women like you to benefit from the results of the project.

### **Confidentiality**

The research being done in the community may draw attention and if you participate you may be asked questions by other people in the community. I will not be sharing information about you and your participation to anyone else, neither to other women or Positive Sisters. The research is entirely for academic purposes and your names will not be revealed to anyone. The information that I collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only I will know what your number is, and it will not be shared with anyone.

### **Contact Information**

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me using my email address: [amanda-mariga@hotmail.com](mailto:amanda-mariga@hotmail.com)

**Part II: Certificate of Consent**

I have been invited to participate in a research project about the Positive Sisters project. I have read the preceding information, or it has been read to me. I have had the opportunity to ask questions about it and any question I have asked has been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Number of Positive sister /Match / Key Informant \_\_\_\_\_

Signature of Positive sister /match / Key Informant \_\_\_\_\_

Date \_\_\_\_\_

Day/Month/Year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what will be done during this interview.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been forced into giving consent, the consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Name of Researcher/person taking the consent \_\_\_\_\_

Signature of Researcher /person taking the consent \_\_\_\_\_

Date \_\_\_\_\_

Day/Month/Year