Experiencing life as migrants living with HIV in Sweden

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To those who are struggling to find the words,

and those who are not being heard.

ABSTRACT

The focus of this thesis is on the life situation of migrants living with HIV in Sweden. The overall aim of this thesis was to explore the knowledge of HIV-positive migrants' life situation in Sweden, with a focus on health and well-being as well as healthcare contacts. This thesis comprises four studies. Studies I-III were designed as explorative and descriptive with Study IV being designed to be quantitative. **Study I** is a Grounded Theory study based on the encounters of migrants living with HIV with the Swedish health care system (no=14). The results indicated that experiences of discrimination in general health care were combined with an appreciation of the free access to advanced ART. **Study II** is an explorative qualitative study based on the experiences of HIV care givers (no=14) in providing care to migrant patients living with HIV. Data was analyzed using content analysis. The findings revealed the challenges that arise due to limited time available for adequate communication and support for the patients, related to the patients' perceived stigma and their migrations status. Further, the process of migration causes various levels of socio-economic vulnerability for the patients. **Study III** explores the life situations of migrants living with HIV (no=14). Data was analyzed using content analysis. The results indicate vulnerability in social relationships, due to perceived stigma and the stigmatized condition as well as the lack of a social network and social support. Fear of disclosure of HIV was also experienced in everyday life. This resulted in loneliness and difficulty finding a partner and close friends. Further, the findings revealed that migrants living with HIV are also resilient. It revealed their struggle to cope with the existential uncertainty, to live a life with integrity, and to look positively at life. **Study IV** is a quantitative study from the national health survey InCare HIV. It investigated whether there were differences in Quality of life between HIV-positive migrants and HIV-positive Swedish-born receiving care and treatment at the Infectious Disease Clinics in Western Sweden. The migrants were younger, a higher proportion was female and a higher proportion with heterosexual route of transmission compared to the Swedish-born. They had lower CD4-nadir and more frequent detectable viral load indicating inferior treatment outcomes. Further, migrants reported both side-effects and missed doses of antiretroviral treatment more often and a subgroup had lower satisfaction with their physical health. On the other hand, the migrants had higher satisfaction with their sexual health.

In conclusion, the need to define the different forms of limitations and discrimination towards migrants living with HIV within the general health care system and other arenas should be combined with holistic and individualized social support in order to strengthen their social networks and offer patient associations. Targeted interventions are needed to enhance the healthcare professions and social actors’ access to updated information and knowledge within the field of HIV, vulnerability, racism and migration. Migrants living with HIV and their self-defined needs should be prioritized in the context of treatment, care and social support.

Keywords: migrants living with HIV; life situation; health care system; Sweden

CONTENTS

LIST OF PAPERS

This thesis is based on following four studies:

I. Mehdiyar M, Andersson R, Hjelm K, Povlsen L. HIV-positive migrants' encounters with the Swedish health care system. Glob Health Action. 2016; 9: 31753.

II. Mehdiyar M, Andersson R, Hjelm K. Swedish HIV Caregivers' Experiences of Providing Care to HIV-Positive Migrants: A Qualitative Study. J AIDS Clin Res. 2018;9(2):758.

III. Mehdiyar M, Andersson R & Hjelm K. HIV-positive migrant's experience of living in Sweden. Revisions submitted.

IV. Mehdiyar M, Andersson R & Yilmaz A. Quality of life among migrants and Swedish born people living with HIV in Western Sweden – a register based study.

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ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral treatment
CD 4	Cluster of differentiation 4
HIV	Human immunodeficiency virus
InfCareHIV	Swedish National Quality Assurance Registry InfCareHIV
PLHIV	People living with HIV
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
QoL	Quality of life

INTRODUCTION

HIV from a Global perspective

Due to the progress in HIV-treatment during the past decades, HIV can become a chronic disease with effective antiretroviral therapy [1, 2)]. Consequently, the life expectancy of people living with HIV (PLHIV) is approaching that of the general population in the West [3]. However, the study revealed that the life expectancy of the most vulnerable group of people living with HIV in Western countries, such as non–white people and those with a history of drug use, has not yet improved to the same extent [3].

The global commitment to achieving the 90–90–90 targets by 2020 [4] has significantly improved access to antiretroviral therapy worldwide, and decreased HIV-mortality during the last 10 years (see figure 1). The 90–90–90 target is based on the following: > 90% of PLHIV are aware of their HIV status; >90% of those people who are aware of their HIV-positive status are accessing treatment; and > 90% of those people receiving treatment have suppressed viral loads.

On the other hand, even though access to advanced HIV-prevention, treatment and care services has increased during the last decade, there are still many people who do not have access to these services [4].

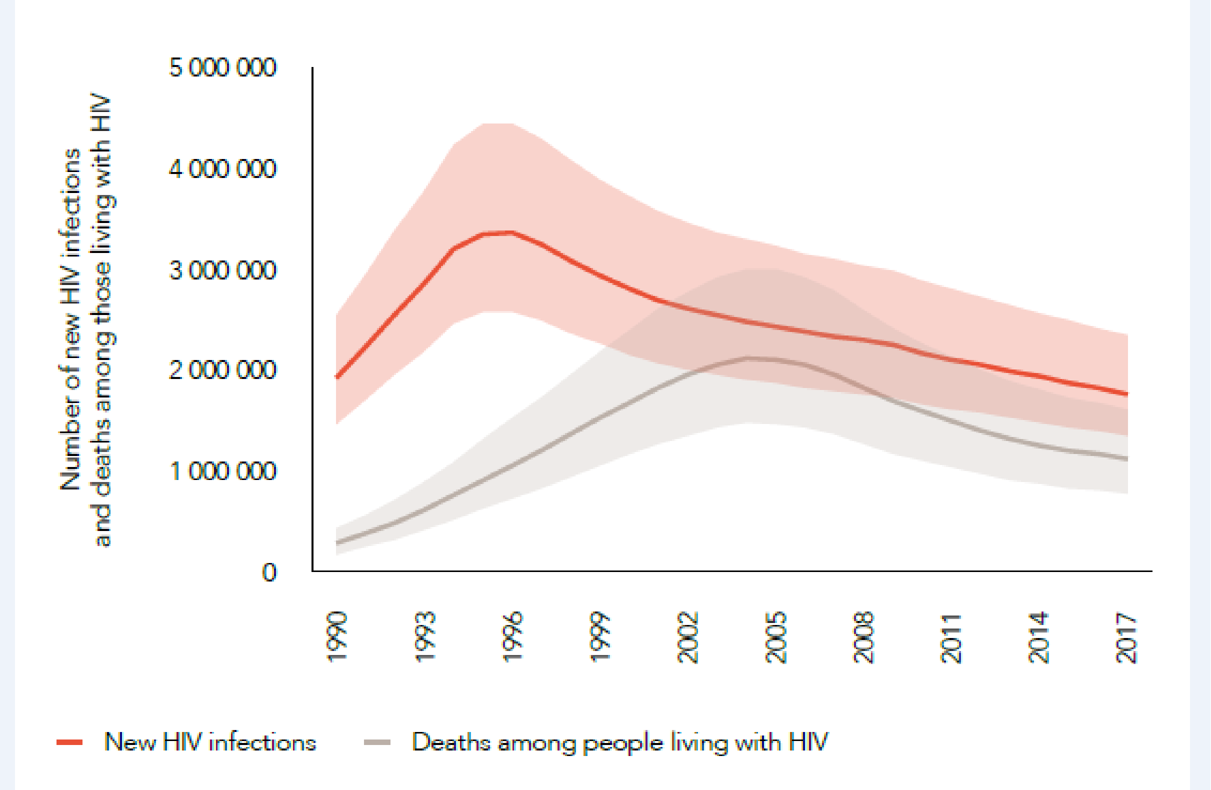


Figure1: Number of new HIV infections and deaths among PLHIV. Source: UNAIDS 2018.

HIV still remains as a global health challenge since the start of the epidemic in 1980. In total, 77 million people have become infected with HIV, 35 million people have died from HIV-related diseases, and 36.9 million people are living with HIV [4].

Gender inequalities, power relationships, and poverty expose women and other vulnerable groups at high risk of HIV in many countries. Evidence shows that women's socioeconomic status such as their financial dependency on men in many countries is fundamental in terms of HIV risk [5, 6]. Further, meta-analysis of studies found that intimate partner violence was connected to lower treatment outcome and lower levels of viral suppression [7].

Moreover, HIV can become a chronic disease for many people with access to treatment and care. However, this is still associated with a significant stigma globally, which negatively impacts on the psychosocial life and well-being of PLHIV's [8, 9. 10].

HIV and stigma

Suffering from discrimination and psychological disorders as a consequence of stigma has also been a part of the life for many PLHIV's globally. Further, it has caused obstacles to prevention and effective treatment and care through the decades, even within the most advanced health-care systems [1,11].

A systematic review on HIV stigma among healthcare providers revealed that HIV-related stigma towards PLHIV varied according to race, gender, provider category, and the clinical context. It also showed that lack of HIV-stigma training among the healthcare providers caused more stigmatizing behaviors toward the patients [12].

The term, stigma was first defined and used by Goffman [13], and refers to *"the phenomenon whereby an individual with an attribute which is deeply discredited by his or her society is rejected as a result of the attribute"* (13, page 123).

Thus stigmatized individuals are considered to be different from others in a negative, undesired and shameful way [13]. Further, public stigma is defined as the response by society to stigmatized individuals based on negative and discriminative attitudes, and perceived stigma refers to individuals' awareness of the public stigma [14].

Stigmatizing attitudes towards PLHIV are strongly linked to overestimating and misunderstanding the risk of HIV transmission. Further, HIV is also correlated with the negative attitudes towards vulnerable groups who are disproportionately affected by the epidemic, among others, gay men, migrants, injecting drug users, sex workers and prisoners [4].

However, in the context of HIV, the influence of HIV-related stigma varies in relation to the affected individual‘s socio-economic status, access to networks and education, and these determine the level of vulnerability [15]. For instance, the intersections of HIV with other forms of social marginalization, such as racism, sexism, homophobia, transphobia and the power relationships determine the level of stigma and its mechanism [16, 17, 18]. In this context, the conceptual framework of HIV-stigma has been developed in research and is being used to explain the intersection of various forms of stigma on the individuals’ life, their well-being and quality of life [19, 20].

Moreover, although HIV-related stigma and its causes is well-known, there is challenge faced by all countries which is aimed at decreasing the levels of stigma [8, 9, 10]. A recent report from UNAIDS [21] shows that despite decades of public information campaigns and efforts to raise awareness and knowledge, the persistence of irrational fears of HIV infection and the judgement attitudes towards PLHIV give rise to stigma and these are the main obstacles impeding HIV-prevention and care.

This report has revealed that PLHIV are exposed to discrimination in all sectors of society, from public sectors to health-care workers, the workplaces, schools and communities [21].

As the result, PLHIV in countries with high levels of HIV-related stigma are 2.4 times more likely to delay in seeking treatment and care [22].

Migration, health and HIV

The term, migration includes a wide variety of movements and situations involving people with different backgrounds and life situations [23]. According to The UN International Organization for Migration (IOM), the term migrant explains different forms of situations in the context of migration [23]. It refers to both forced and voluntary migrants. Forced migrants (refugees and asylum seekers), refers to people who are forced to move from their home as a consequence of war, persecution, poverty, lack of human rights, environmental disasters etc. Further, the term migrant also refers to voluntary migrants (immigrants) that often leave their home in search of better jobs and living conditions [23].

International migration is a complex phenomenon. It contributes to growth and opportunities for governments, businesses and communities [23]. Approximately 1 billion people in the world are considered to be migrants. Of these around 244 million are international migrants, and 740 million are living as internal migrants within the same country [23]. Migration has developed people’s lives, societies, and has created opportunities for millions of people for a safe and meaningful life throughout history [23]. However, the social contexts and circumstances in which migration takes place vary.

The UN Migration Agency report [23] describes the current conditions of migrants:

"Barely a day goes by without multiple media reports – whether in traditional or newer forms of media – focusing on aspects of migration, frequently on negative aspects. While this may reflect, in part, the changing nature of migration in certain regions of the world, it is important to be aware how media and news are constructed and produced – news reporting continues to place greater emphasis on "bad" news. Social media is widely acknowledged as a forum that provides little or no filter, with the consequence that there tends to be much greater emphasis on opinion than on facts and analysis." (page 1)

The diversity among migrants in Europe is high with varying degrees of vulnerability [24]. Generally, social factors such as exclusion and marginalized social identity have negative impact on the health and well-being of ethnic minorities, migrants, and especially PLHIV [25, 26]. Further, in the context of health equity, evidence reveals that focus must be on the social process causing exclusion and discrimination rather than addressing the characteristic of excluded people [27].

.Generally, poor health among migrants and ethnic minority groups in Europe compared to the majority population is well-known [28, 29]. Nevertheless, several studies from high-income countries, among others USA, Canada, UK, and Australia reveal "healthy immigrant effect". 'Healthy immigrant effect' refers to the evidence that migrants who have recently arrived in the country have, on average a better health status compared to native-born people, although their health status is diminished after a time following immigration. [30, 31, 32, 33]. However, refugees living in refugee camps generally have poor health upon arrival in the community [34].

The social determinants of health is a developed concept that describes the impact of inequality in terms of life conditions and its negative impact on people’s health and well-being in different communities throughout the world. It describes health inequities within health care system and also the circumstances, in which individuals are born, grow and age [35]. For instance, gender, age, race/ethnicity, income, occupation and the power relationships produced by these determinants, have a significant impact on the individuals’ health and illnesses [35, 36].

Further, several studies illustrate the challenge linked to biomedical research paradigms that fail to consider the social and economic context of health and illness, and tend to ignore the unequal power distributions and the negative impact of these on health inequities [36, 37].

Social, economic and political factors in both the country of origin and destination countries increase migrants’ risk for HIV infection [21]. For instance, HIV prevalence is higher among migrants from countries with a severe HIV epidemic. In addition, there is an increased risk for migrants to get infected with HIV in their country of destination, or on the journey including at refugee camps [21].

Moreover, the vulnerability of migrants to HIV infection globally has been increased by barriers to accessing healthcare services, HIV prevention, treatment and HIV-related information and support [38, 39]. For example, studies from KwaZulu-Natal, South Africa reported that, in the areas where migration was frequent, HIV prevalence among migrant women aged 25–29 was as high as 63% [40]. This reveals migrant women vulnerability to HIV based on gender, age, and poverty.

Migrants living with HIV in Europe and Western countries

Migrants are more often infected by HIV than the general population, especially in Northern and Western Europe, both due to the epidemiological patterns in the migrants' countries of origin and the pre-, inter- and post-migration factors [21]. Studies within Europe have shown that late HIV-diagnosis and treatment are more common among migrants, compared to the native-born [41]. It indicates that the combine effects of difficult living conditions and limited access to health care for refugees and undocumented migrants in Europe have led to delayed care [42].

Further, the vulnerability to HIV, particularly among refugees and undocumented migrants in Western countries, due to the language barrier, limited access to health care, lack of social protection and social exclusion, has become enhanced in the process of migration [21]. Studies have shown that migrants with HIV–tuberculosis coinfection were especially prone to treatment failure, drug-resistant tuberculosis and premature death [43, 44]. In addition, a systematic review of studies revealed that discrimination within health care services causes barriers to HIV testing and counseling among migrants in Europe [45].

On the other hand, access to health care is a complicated phenomenon and includes many factors surrounding people's lives, such as psychological and social factors having a significant impact on the treatment delivered to migrants living with HIV in Western countries. There is still a minority of PLHIV living in these countries who have access to HIV care, yet who choose not to use the treatment [46].

For instance, a lack of willingness to accept medical care among Sub-Saharan migrants in Western Europe, and low rates of testing were found to be caused by a fear of death and disease, as well as a fear of stigma and discrimination [47]. Another study on structural barrier to HIV treatment among Hispanic women and Latino Americans in USA showed that the late uptake of medical care was related to the fear of deportation, language barriers and the HIV-related discrimination within health care services [48]. In addition, barriers to testing and care among African migrants in the Netherlands was found to be grounded in a fear of death and disease, and a fear of stigma and discrimination within their own communities [49].

A systematic review of studies found that ethnic minorities and migrants from low HIV prevalence areas are also at increased risk of HIV infection in Europe because of their socio-economic vulnerability [50]. Moreover, racism and cultural and linguistic barriers increase migrants' vulnerabilities in an HIV context [50]. Moreover, in the case of migrants in Western Europe, there are further obstacles to HIV-prevention, treatment and care that are within the legal frameworks, immigration policies, and migrants' social circumstances (51).

Further, a review of studies revealed that HIV-treatment outcome is lower among migrants from low- and middle- income countries living in high-income countries, due to limited access to care and stigma [52]. Further it indicated lack of evidence on proper interventions for the most marginalized group of PLHIV.

It is therefore important to identify the structural barriers to HIV care among the most vulnerable group of migrants, in order to enable individualized and optimal care and social support to be provided in the various different communities. From a health promotion perspective, participation and empowerment are the key issues in increasing well-being while reducing vulnerability (53).

HIV in Sweden

In 2018, 481 new cases of HIV were diagnosed in Sweden. An average of 453 new HIV- diagnoses per year has been reported during the past ten years [54]. The prevalence of HIV is low in Sweden, approximately 0.07 percent of the population [54], yet there are challenges in terms of effective delivery of HIV-prevention and care.

The so-called key population at risk of HIV-infection in Sweden is described by The Public Health Agency of Sweden including ‘men who have sex with men’, ‘injection drug users’ and ‘migrants’ [55]. However, a critical study [56] on the Swedish HIV /AIDS policy discourses revealed how the policy documents present different groups to be especially at risk, and explained the problem with reproducing stereotypes of different groups, such as ‘men who have sex with men’, ‘injecting drug users’ and ‘immigrants’ in the Swedish HIV /AIDS policy. The study has also indicated that *“since this discourse occurs at the level of official policy it forms part of wider machinery that produces and reproduces power relations in Swedish society.”* [page 73].

HIV-treatment has improved in Sweden. A study has found that, in 2016 Sweden was one of the first countries to diagnose 90% of all HIV cases [57]. Of these, 99.8% were undergoing HIV-care, and in 95% of treated cases, HIV viral load was undetectable. Even though Sweden has achieved the “90-90-90” targets [4], the health-related quality of life of PLHIV still needs to be improved.

A recent study on health related quality of life of PLHIV in Sweden found that QoL of PLHIV was generally high, although this was significantly affected by HIV-related symptoms and side-effects of ART [58]. Moreover, despite improvements in HIV-treatment, a study on HIV-associated stigma in Sweden indicated that the continued effects of stigma were reducing the health-related quality of life of PLHIV [59].

HIV is classifies as dangerous to public health and submitted to mandatory contact tracing, according to The Swedish Communicable Diseases law [60]. Thus, people living with HIV have the duty to disclose their HIV status to their sexual partners, which further increases the vulnerability of these people in their social lives. This law is considered to be among the most restrictive in the world [61]. However, due to the evidence as to the minimal risk of transmission when persons are receiving ART with repeated undetectable viral loads in the blood [62, 63], the law has been modified to some extent since 2013.

This means that the physicians at the Infectious Disease Clinics treating these patients determine the individual restrictions, based on treatment results [64]. According to The Public Health Agency of Sweden in 2018, 83% of the treating physicians at the infectious disease clinics had excluded one or more patients from the duty to inform sexual partners about their HIV status [65].

Migrants living with HIV in Sweden

The higher prevalence of HIV among migrants in Sweden mirrors the global epidemics [66, 67]. A study has found that more than half of Swedish patients with HIV were diagnosed late, and that the majority of the patients diagnosed late were migrants. [68]. Late HIV-diagnosis causes higher levels of mortality and morbidity among PLHIV.

The health inequalities between Swedish born and migrants are not limited to HIV-infection. Evidence shows that health inequality exists in nearly all health-related issues [67] and that it is linked to social determinants of health and the role of this in causing these inequalities [69, 70]. Social determinants of health also describes how the health of individuals is profoundly affected by the health care systems, and also the conditions in which people are born, are raised, live, work, and age [69, 70].

Few studies are focused on the migrants living with HIV in Sweden and their life situations, despite their late diagnosis and evidence of higher degrees of health vulnerability and the need for tailored HIV-prevention and care. A more integrated and comprehensive awareness of the experiences of migrants in general and migrants living with HIV in particular is warranted. This would increase our understanding of the structural and hidden barriers causing these health inequalities, as well as options to address them in order to promote well-being.

THEORETICAL FRAMEWORK

The thesis is based on the following theoretical framework:

Social constructionism

Social constructionism is a theory of knowledge in sociology that emphasizes the importance of critical attitude for developing our perceptions of the world and ourselves, and aims to challenge the conventional perceptions of knowledge and its formation [71]. According to social constructionism, the way we understand and categorize the world is historically and culturally specific and relative. Thus, knowledge is regarded as a product of interactions between people under specific socio-economic conditions [71].

In a constructive approach, individual and social phenomena should also be studied through the subjective experiences of individuals, and not only through the perspective of those with privilege and the power. Moreover, a constructivist perspective emphasizes the contextual dependence of culture and cultural identity as a social construction that is formed under specific circumstances [72]. Further, the theoretical framework of discourse analysis describes relationships between language, practice and power in creating social reality [73].

Intersectionality

Intersectionality is a theoretical framework which is developed from black feminism in sociology [74], and provides insights into the intersection of power structure, social inequality and social determinants of health. An intersectional approach considers the social identities based on of gender, race, class, sexual orientations, and other social constructed identities that overlap each other and create a complex system of unequal social relationships between groups of people, responsible for social injustice and inequalities [75]. Intersectionality describes the privilege of the dominant group's access to more comprehensive material and social resources that constantly perpetuate power and powerlessness in many people’s lives [75].

Further, the intersectional approach in HIV describes how the intersections of multiple marginalized social identities and social categories create a complex system of oppression and its consequences on health and well-being of PLHIV [26]. Hence, an intersectional approach views the subjective experiences of the individuals as essential in exploring and identifying the foundations of obstacles to HIV-treatment, care and preventions [76].

Care and the caring process

Care and the caring processes is the oldest phenomenon in human history. To confirm the existence of others through care and the caring process is considered to be a very natural and human characteristic [77]. The realization and preservation of the idea of care is an expression of true humanity and something that confirms the caregiver as a human being [77].

Moreover, the theory of transcultural care is developed in nursing research and highlights the fact that human caring is universal with different expressions, processes and patterns among different cultures [78]. It emphasizes that human beings cannot exist detached from their cultural background and social relationships. Thus the provision of holistic care for people requires consideration of the physical, psychological, cultural, social and environmental dimensions of every context of an individual’s life [78].

Person-centered care has been developed as a philosophy of care with a framework based on the humanistic ideas that all people are unique, worthy, competent and equal [79, 80]. Person-centered care emphasizes every human being’s unique potential, resource and need. Hence, people are considered to be at the center of planning and decision as an equal actor during the caring process. Further, caring processes should be focused on each person's own perception and needs through the communication, as the key issue in person-centered care [81, 82].

The Health Care Act in Sweden defines the aim of a good health care system as providing equal health care for the entire population, and states that this should be based on equal values and equal dignity for all people [83]. It also emphasizes the fact that people with the greatest need in terms of care and treatment should be given priority in every context.

RATIONALE

Migration means lifelong challenges of varying degrees for the individuals. The migration process, a new country, community, laws, culture, language, uncertainty, lack of a social network in combination with stress caused by xenophobia, causes vulnerability and deteriorating health in different respects. Further, HIV is a complex disease with well-known social consequences which, in combination with migration exposes the individuals to an even higher degree of social and psychological vulnerability.

Thus, the complex system of social vulnerability of migrants living with HIV, requires an in depth awareness and understanding of the subjective experiences of these individuals, in order to identify their needs and to provide a tailored social support which aims to enhance their empowerment and well-being. Further, there is limited knowledge concerning migrants living with HIV in Sweden and their life experiences, which needs to be improved. A deeper understanding of the subjective life experience of migrants living with HIV is needed in order to widen the perspective and adapt the health care and social resources available to provide holistic support for migrants living with HIV.

AIMS

The overall aim of this thesis was to explore the knowledge of HIV-positive migrants' life situation in Sweden, with a focus on health and well-being and healthcare contacts. This thesis is based on four studies.

Specific aims

- To deepen the knowledge of HIV-positive migrants' experiences of their encounters with the Swedish health care system (I).

- To explore the experiences of HIV care givers in providing care to HIV-positive migrants (II).

- To describe HIV-positive migrants' experiences of their life situations (III).

- To investigate whether there were differences in QoL between HIV-positive migrants and HIV-positive Swedish-born who receive care and treatment at the Infectious Disease Clinics in western Sweden (IV).

METHODS

Research design

In order to explore, describe and improve our understanding of migrants living with HIV in Sweden, three studies with qualitative explorative design (I-III) were chosen in relation to the explorative aim of the studies, and one study (IV) was performed with a quantitative design.

Study I was performed by qualitative Grounded Theory [84], Study II and III was qualitative explorative, performed by content analysis [85, 86]. Study IV was based on the national quality assurance registry, InfCare HIV [87].
See table 1.

Qualitative semi-structured interviews were used for data collections in Study I and III to explore the life experiences of migrants living with HIV from different perspectives including their life experiences and their experiences of their encounters with the Swedish health care system. In Study II, semi-structure focus group interviews were conducted with HIV-care givers at the Infectious Disease Clinics in Western Sweden.

Study IV was a quantitative approach based on the data collected from the national quality assurance registry InfCare HIV in order to investigate whether there were differences in sociodemographic, treatment and care, and quality of life (QoL) between HIV-positive migrants and HIV-positive Swedish-born receiving treatment and care at the Infectious Disease Clinics in western Sweden.

Table1. Methodological research design, Studies I, II, III and IV.

Study	Study design	Study area	Study population	Method of data collection	Method of data analysis
I	Explorative and descriptive	Infectious Disease Clinics in Western region	14 HIV-positive migrants -29-55 years -7 women -7 men	Individual semi-structured interviews	Qualitative Grounded Theory
II	Explorative and descriptive	Infectious Disease Clinics in Western region	14 HIV care givers; nurses and social workers	Focus group interviews	Qualitative content analysis
III	Explorative and descriptive	Infectious Disease Clinics in Western region	14 HIV-positive migrants -29-55 years -7 women -7 men	Individual semi-structured interviews	Qualitative content analysis
IV	Quantitative	Infectious Disease Clinics in Western region	839 HIV-positive patients -540 migrants -299 Swedish-born	National quality assurance registry (InfCare HIV)	Descriptive statistical analyses

Study I- III

In Study I, a Grounded Theory approach was used [84] to deepen the knowledge regarding HIV-positive migrants' experiences of their encounters with the Swedish health care system in Western Sweden. Grounded Theory is an explorative method for generating a deeper understanding of the social processes whereby people live their lives and their responses to it [84]. It is a systematic methodology for the construction of a theory or model in different research areas with limited knowledge available, using iterative cycles of abductive reasoning through the analysis of data.

Study II was a qualitative study performed with content analysis using focus group interview [85] to explore HIV-care givers experiences of working with HIV-positive migrants in Western Sweden. The dynamic group support and interaction is based on focus group interviews and involves remembering events, sharing experiences and generating detailed data, rather than individual interviews [85].

Study III was performed with content analysis which is used as a research method for generating awareness and new insights in order to make a representation of the facts through replicable and valid inferences of data to their context [86].

Data collection and participants (Study I-1I1)

Qualitative semi-structured interviews were applied in Study I-III in order to acquire a deeper understanding of the experiences of the persons studied. The participants in Study I and III were 14 HIV-positive migrants including seven women and seven men. The participants were aged between 29 and 55 years, and had different backgrounds, education and socioeconomic status, and had been living in Sweden for between 2 and 20 years. The participants were contacted and recruited from 2011 to 2014 in three Infectious Disease Clinics, in Western Sweden.

Agreement to contact and recruit HIV-positive participants for the study was obtained from the heads of the clinical departments in Western Sweden. All the patients with immigrants' background were given information about the study by the nurses. A letter with information about the study, in English or Swedish was given to all the HIV-positive migrants. Those patients deciding to participate in the study were advised to contact the researcher directly by telephone or via the clinic nurses. Participants were originally from the following regions of the world: Africa (n=10), South America (n=2), South East Asia (n=1), South East Europe (n=1).

Two interview guides were developed for Study I and III based on the research questions and these were reviewed. A pilot interview was conducted before the interviews, and the interview guides were revised. The following three main themes covered the interviews in Study I: How do you perceive your contacts with the health services in Sweden? How have you experienced the support provided by the Swedish health care system? What difficulties have you experienced in your contacts with the Swedish health care system?

The interviews in Study III were covered by the following three main themes: How do you perceive your life situation in Sweden? How would you perceive your relationships with your family and friends? What difficulties have you experienced in the new community? The questions provided an initial context for the interviews. This was followed by additional follow-up questions which were extended to include more in-depth discussions [84, 86].

The sample size of the studies was determined on the basis of the information required in order to answer the research questions with sufficient certainty, and data collection continued until analysis of data indicated that no further information had been added [84, 86]. The participants chose a place that was convenient for them for the interviews to take place.

The process of data collection in Study II began with an invitation to all the staff members who were involved in the treatment and care of HIV-positive migrants at the four Infectious Disease Clinics in Western Sweden to participate in the study. One clinic did not respond to the invitation. Nurses and social workers at the other three clinics agreed to participate in the study, but the physicians declined, citing a lack of time.

The focus-group interviews were conducted in 2013-2014. The open questions in the focus- group interviews were as follows: How do you perceive your work with HIV-positive migrants? How do you view the possibilities to support HIV-positive migrants and attend to their needs? How do you perceive the opportunities and challenges in working with HIV-positive migrants? – at an individual level? –at a structural level? The questions prepared a framework for the discussion and continued with follow-up and comprehensive questions.

Fourteen caregivers participated in four Focus-group interviews and each focus group interview consisted of between three and five participants. The first focus-group interview was performed as a pilot. The interviews lasted almost one hour, and were audio-taped and transcribed verbatim.

Data analysis (Study I-III)

Data analysis in Studies I-III was performed in parallel with data collection and continued until it indicated that no further information had been added [84, 85, 86]. The interviews (I-III) were transcribed verbatim and were read in their entirety several times in terms of their context and in relation to the aim of the studies, in order to give a broad picture of the data. Further constant comparison was used during the process of data analysis (I-III).

The analysis of data in Study I was performed according to constructed Grounded Theory (84) and included open coding and theoretical coding. In open coding the words or phrases were identified. The next step was to perform an analysis of the concepts and their relationships. This process continued until the core category as deeply abstracted category that explained the recorded variation of data emerged. In theoretical coding, the relationships between the codes and their properties was conceptualized and developed into categories [84]. Analytical memo was written during the data analysis as an important structural level for providing important connection between coding during the process of data analysis [84].

Focus group interviews in Study II were analyzed as described by Krueger & Casey [85]. This method is based on a detailed analysis of the content and their relationships within the text [85]. Further, sections with related meanings were grouped together according to their differences and similarities. Codes were assigned to each of the meaning units. The process continued by sorting the codes into sub-categories based on their relationships, and sub-categories with similar contents were sorted into categories.

Data analysis in Study III was performed according to content analysis [86]. The content of the data was analyzed according to its context. The context is emphasized in the content analysis as being central, even though it is considered to be important in all qualitative research [86]. Thus, the analysis of the data involved identifying the content by means of differences and similarities. Further, textual units were identified and content was named with codes. Similar codes were sorted into sub-categories according to their relationships, and similar sub-categories were sorted into categories and named as closely to the text as possible reflecting their content.

Study IV

Study IV was based on the national quality assurance registry, InfCare HIV [87]. This study compared differences in QoL between Swedish-born and migrants living with HIV, The data were collected from a total of 839 patients including 540 migrants and 299 Swedish-born.

Data collection and participants

Inclusion criteria was all the individuals with known HIV-infection receiving care at the four Infectious Disease Clinics in the Western region of Sweden between March and June 2018. This includes all Swedish-born and migrants with or without a residence permit. From InfCare HIV, we collected information relating to age, sex, route of HIV transmission, type of ART, plasma HIV RNA levels, lowest CD4+ T-cell count (nadir), AIDS-defining diagnosis, and hepatitis B and C sero-status.

InfCare HIV also includes an annually health-related quality of life (QoL) questionnaire, since 2007. The questionnaire is available in Swedish and English, and comprises six questions covering general somatic health, psychological wellbeing, satisfaction with sexual life, possible side-effects of ART, adherence to treatment, and level of involvement in the planning of their care.

Data analysis

In Study IV, the data was analyzed by Descriptive Statistic to compare the differences between Swedish- born and migrants living with HIV. Further, the data analysis was performed using Chi-squared and Fisher test for categorical data and Mann-Whitney and Kruskall-Wallis for numeric variables.

RESULTS

Study I

‘A hybrid of access and adversity’ has emerged as the core category of this study, followed by three categories, and describes the dual experiences of patients’ encounters with the Swedish health care system (Figure 2). The appreciation for access to advanced, dignified and free access to HIV-treatment and care at the Infectious Disease Clinics were opposed by discrimination and structural limitations within the general health care system. The terms, ‘access’ and ‘adversity’ is used to describe these experiences and the inherent tension between them combined with the fear, distrust and caution related to the Swedish “Diseases Act”.

Gratitude towards access to free HIV treatment and care was extensive among the patients in the study. However, the degree of gratitude differed according to the patients’ backgrounds and the HIV situation in their countries of origin. Those who had been diagnosed with HIV before moving to Sweden, and who had experienced insufficient HIV treatment and care in their countries of origin had a greater appreciation of the HIV treatment available in Sweden.

On the other hand, the experience of discrimination in general health care, outside of the infectious diseases clinics, limited the participants access to health care services. This includes primary health care, dental care, and other specialist care facilities. Further, the impact of the Swedish Disease Act was mainly experienced by unmarried participants, and was described as being an obstacle to their well-being.

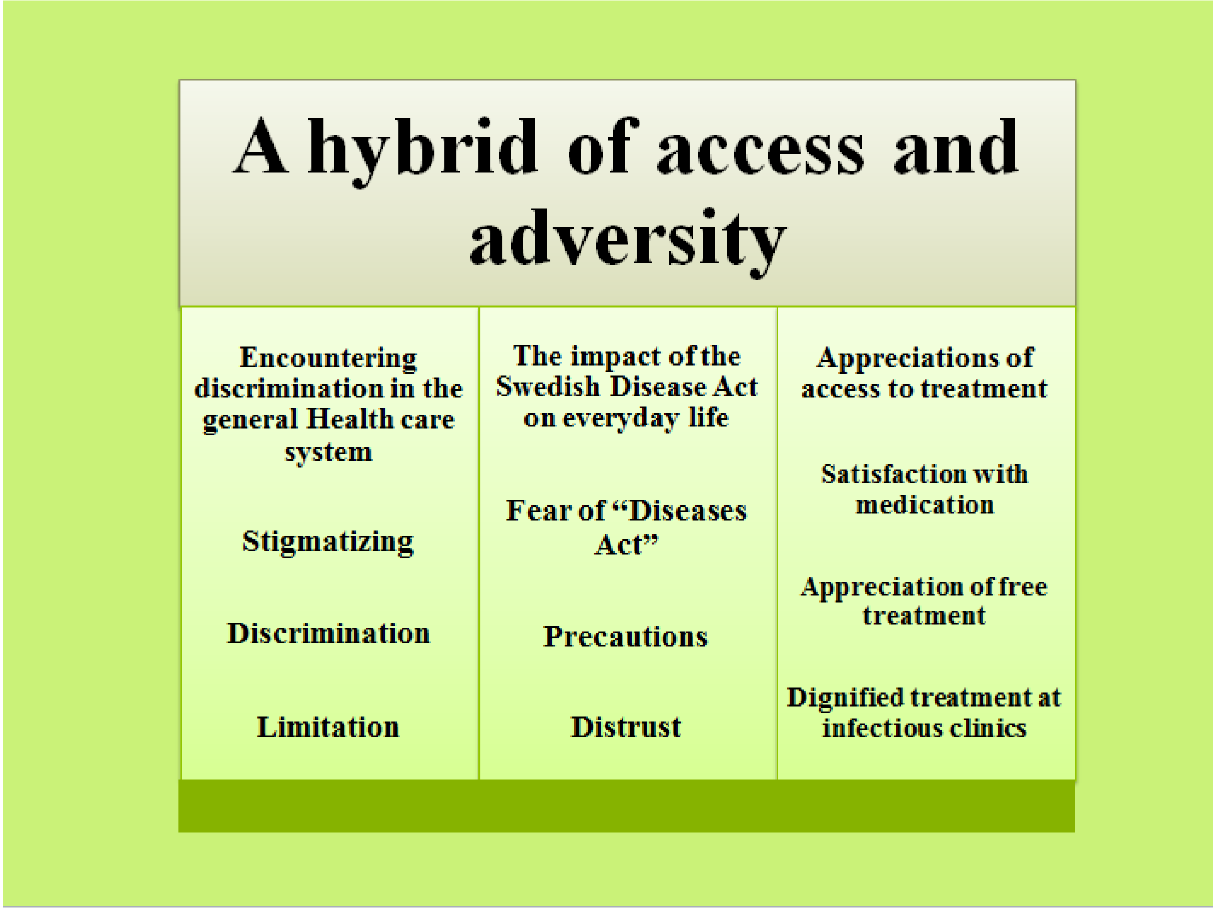


Figure 2: The core category and the three sub-categories, Study I.

Study II

The results of this study were illustrated in three different categories and subcategories, as shown in figure 3. The first category was the HIV care givers' general challenges in lacking the time for providing communication and support for their migrant patients who are in need of more support.

The second category revealed the experiences of challenges of the patients' migration status, due to the patients' higher degrees of vulnerability in various different ways and thus their need for extra social support, in addition to medical treatment. Patients' migration status included a wide range of situations, from asylum seekers and undocumented migrants to migrants with a residence permit and citizenship and also patients who had lived in Sweden for a short or a long time. Further, the result of this study showed migrant patients' lack of access to a social network and patient associations, which has caused them to be deprived of the information, knowledge and support they needed.

Moreover, social workers' different role at the Infectious Disease Clinics was expressed as being somewhat contradictory. Their authority task at the clinic that was aimed at tracing the HIV patients' contacts, could affect social workers' other duty which was supposed to provide the patients with supportive conversation therapy. Since their authority contact tracing role could affect the patients' trust, as a foundation in all supportive conversational therapy.

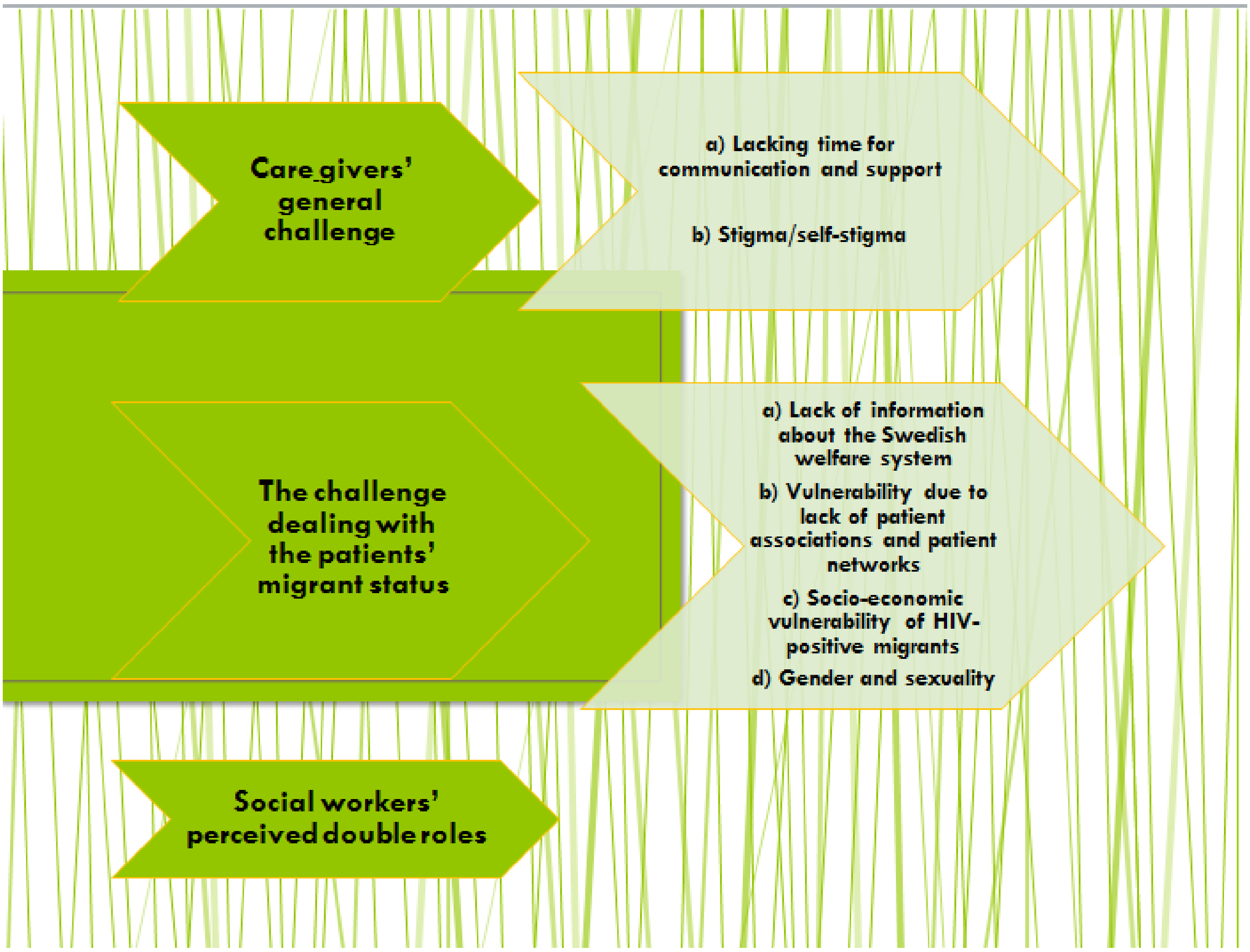


Figure 2: The categories and sub-categories, Study II.

Study III

The results of this study (III) of which the aim was to explore HIV-positive migrants' experiences of their life situations, living in western Sweden, are presented in the following three categories together with sub-categories: Vulnerability in social relationships'; 'Fear of disclosure'; and 'Resilience' (See Figure 4).

Vulnerability in social relationships describes the participants’ experiences of isolation, stigma and the lack of a social network and support, which have made them vulnerable in their social lives. The majority of the study participants were originally from African countries, as these countries are more affected by the endemic. However, socio-economic status determined the degree of vulnerability as well as the need for access to a social support services and network.

Another aspect of social vulnerability was the experience of powerlessness in contact with the different social actors, which was described as the sub-category ‘The gray zone between help and the exercise of power’. Further, ‘loneliness and perceived stigma’ also made the participants vulnerable. They even isolated themselves from their fellow countrymen because of their fear of disclosure of HIV.

The experience of fear of disclosure, was another finding of the study (III), and caused the participants to have difficulties in finding a partner, or close friends. The majority of the participants did not have a partner and they expressed difficulty in finding one. The fear of being rejected and discriminated from a non HIV-positive partner, led to the participants having a strong desire to find an HIV-positive partner.

As result, ‘longing for someone who understands’ was also a need which was expressed by the participants. They indicated their longing for someone to socialize with and to get close to. Someone who was in the same situation and who understood them and whom they could talk to and share their experiences with.

However, the results also revealed participants’ resilience, their struggle to live a normal life with integrity, in coping with existential uncertainty, in their effort to look positively at life, and in the struggle to live a normal life with integrity.

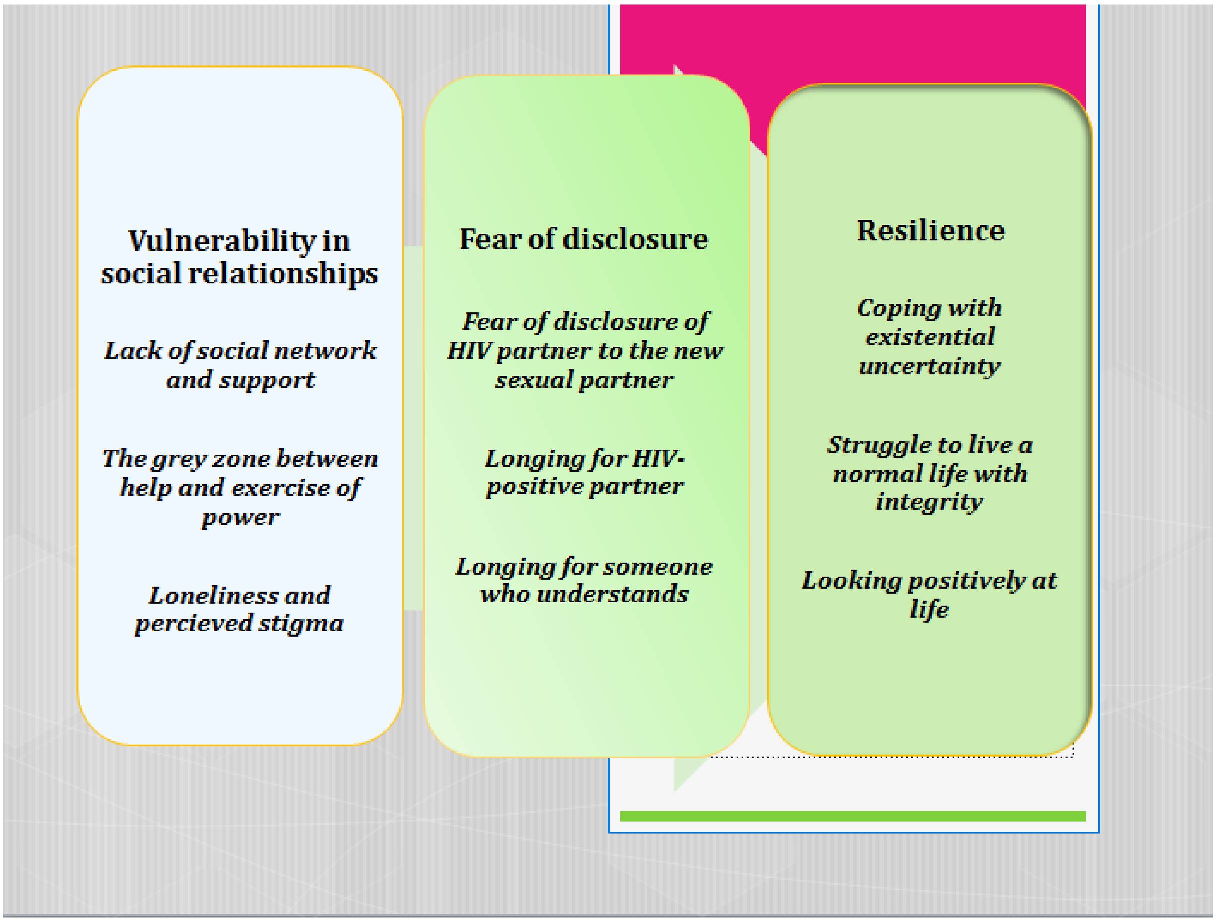


Figure 4: The categories and sub-categories, Study III.

Study IV

The findings illustrated sociodemographic differences between Swedish-born and migrants. The migrants had a median age of 31.8 at diagnosis compared to 37.2 years for patients born in Sweden, and 53.7% of the migrants were women compared to 17.7% of the Swedish born ($p < 0.001$). Heterosexual mode of transmission was more common among migrants (67.4%), compared to the Swedish-born (43.5%; $p < 0.001$). The migrants had a higher prevalence of chronic hepatitis B than Swedish-born (4.5% vs 1.0%); $p = 0.007$).

Further, migrants had significantly lower CD4 nadir compared to Swedish-born (190 vs 220 cells/mm$^{3;}$ $p < 0.01$). Fewer migrants were receiving integrase inhibitors (43.3% vs 50.7%; $p = 0.04$). No other significant differences were found for the other types of ART. HIV RNA for 454 patients at the clinic in Gothenburg showed that, of the migrants 14/222 (6.3%) had HIV RNA > 50 units compared to 8/232 (3.4%) of the Swedish-born ($p = 0.16$).

The QoL health survey revealed that larger subgroups of migrants had either high or low satisfaction with physical health compared to Swedish-born (See figure 5). They reported their physical health to be less often in the middle range ($p < 0.02$). Further, side-effects were more common among migrants (24.4 % vs 15.0%; $p = 0.013$. Among the migrants 84.6 % were compliant with their ART dosing compared to 94.4% of the Swedish- born. No other significant differences were found for the level of participation in the treatment.

Satisfaction with sexual health was higher among migrants compared to Swedish-born ($p < 0.001$). However, more of them did not answer the question about their sexual health (12.0 % vs 5.1%; $p = 0.007$). See Table 2.

No significant difference in psychological health between the two groups was found. Of 277 individuals who had not responded to the questionnaire, 77.5% were migrants ($p < 0.001$).

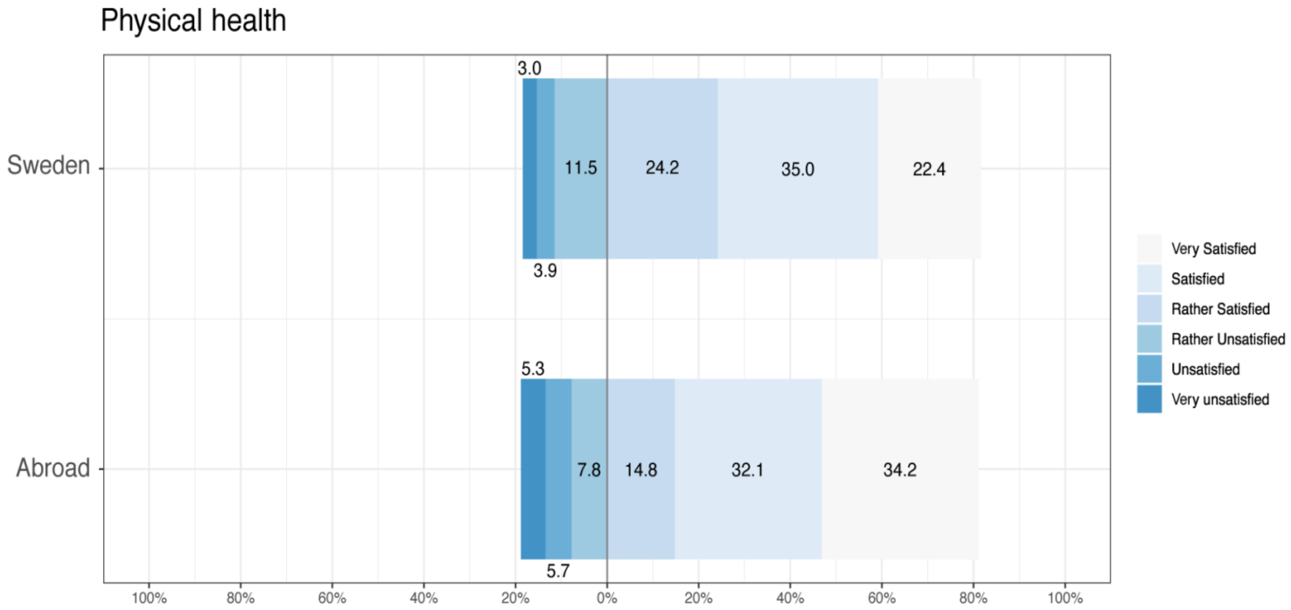
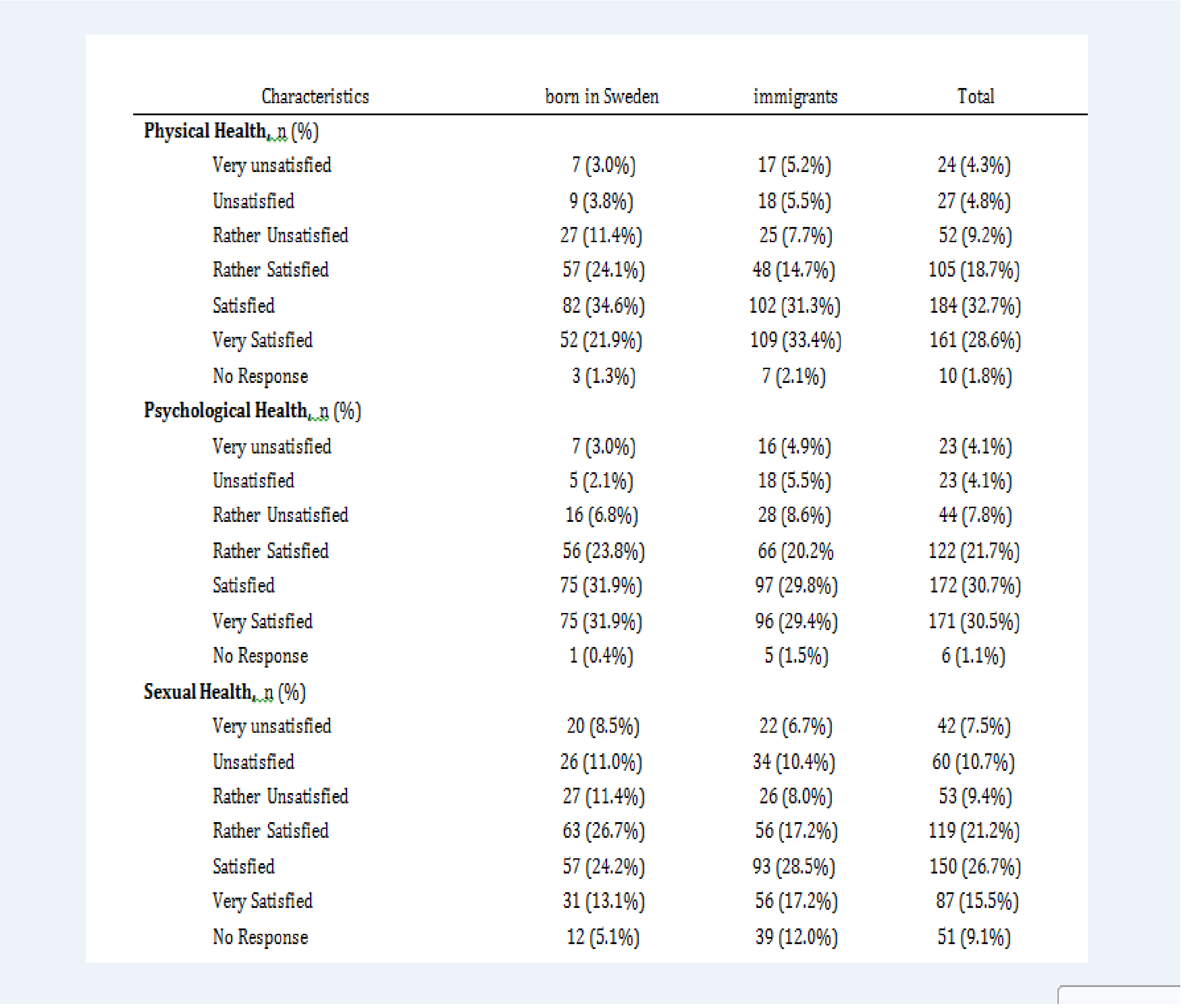


Figure 5: Differences in self-reported physical health between migrants living with HIV and Swedish born, Study IV.

Table 2. Self reported QoL Migrants vs Swedish born, Study IV.



Characteristics	born in Sweden	immigrants	Total
Physical Health, n (%)			
Very unsatisfied	7 (3.0%)	17 (5.2%)	24 (4.3%)
Unsatisfied	9 (3.8%)	18 (5.5%)	27 (4.8%)
Rather Unsatisfied	27 (11.4%)	25 (7.7%)	52 (9.2%)
Rather Satisfied	57 (24.1%)	48 (14.7%)	105 (18.7%)
Satisfied	82 (34.6%)	102 (31.3%)	184 (32.7%)
Very Satisfied	52 (21.9%)	109 (33.4%)	161 (28.6%)
No Response	3 (1.3%)	7 (2.1%)	10 (1.8%)
Psychological Health, n (%)			
Very unsatisfied	7 (3.0%)	16 (4.9%)	23 (4.1%)
Unsatisfied	5 (2.1%)	18 (5.5%)	23 (4.1%)
Rather Unsatisfied	16 (6.8%)	28 (8.6%)	44 (7.8%)
Rather Satisfied	56 (23.8%)	66 (20.2%	122 (21.7%)
Satisfied	75 (31.9%)	97 (29.8%)	172 (30.7%)
Very Satisfied	75 (31.9%)	96 (29.4%)	171 (30.5%)
No Response	1 (0.4%)	5 (1.5%)	6 (1.1%)
Sexual Health, n (%)			
Very unsatisfied	20 (8.5%)	22 (6.7%)	42 (7.5%)
Unsatisfied	26 (11.0%)	34 (10.4%)	60 (10.7%)
Rather Unsatisfied	27 (11.4%)	26 (8.0%)	53 (9.4%)
Rather Satisfied	63 (26.7%)	56 (17.2%)	119 (21.2%)
Satisfied	57 (24.2%)	93 (28.5%)	150 (26.7%)
Very Satisfied	31 (13.1%)	56 (17.2%)	87 (15.5%)
No Response	12 (5.1%)	39 (12.0%)	51 (9.1%)

ETHICAL CONSIDERATIONS

The four studies of this thesis followed the Swedish law of ethics in research regarding humans [88]. Moreover, the studies are also performed according to the Swedish Patients Data Act [89], and principles of Helsinki Declaration [90], among other things, the principles of informed consent, right to self-determination, confidentiality and beneficence.

Study I and III were approved by Regional Ethical Review Board in Gothenburg in 2011, registration number: 681-11. The study participants were informed about the aim of the study orally and in written. Written informed consent was obtained from each participant before the interview.

Study II was approved by the Regional Ethical Review Board in Gothenburg in 2012, registration number: 681-11, T275-12. The participants were informed about the aim of study and the confidentiality and anonymity of the participant were guaranteed. Verbal informed consent was obtained from the participants before each focus group interview.

Study IV was approved by Regional Ethical Review Board in Gothenburg in 2016, registration number: 749-17.

DISCUSSION

The findings of this thesis are unique as they explore the experiences of migrants living with HIV and contribute to the new knowledge relating to the experiences of migrants living with HIV in Sweden, and the challenges they face as well as their needs for well-being.

Summary of main findings

In their encounters with the health care system in Sweden, migrants living with HIV experienced a hybrid of access and adversity (I). Their experiences of discrimination in general health care were combined with an appreciation of free access to advanced ART. Further, the Swedish Disease Act has caused fear, cautions and distrust on their everyday lives (I). Their experiences of their life situations was characterized by vulnerability in social relationships resulting from perceived stigma, their stigmatized condition and also the lack of a social network and social support (III).

Further, fear of disclosure of HIV was experienced in everyday life and this has caused loneliness and difficulties in finding a partner and close friends (III). However, the findings revealed that migrants living with HIV were also resilient and struggled to cope with existential uncertainty, living life with integrity, and looking positively at life (III).

Further, the findings illustrated the challenges faced by the HIV care givers in providing care to migrants living with HIV (II). Their experiences were characterized by challenges as a result of limited time for sufficient communication and support for the patients, and patients' perceived stigma (II).

Moreover, HIV care givers experienced challenges due to their patients' migrations status (II). Migration status was described as the patients' life within the various different contexts of the migration process causing adversity and different levels of socio-economic vulnerability regarding the process of obtaining a residence permit, housing, and their limitations in terms of access to information relating to the general health care system, the Swedish welfare system and also knowledge about the rights and duties prevailing in the new society. In addition, the patients were generally more vulnerable because of their lack of access to patient associations and patient networks (II).

HIV care givers also experienced difficulties in communicating sexual issues with non-Swedish born women at the clinics due to cultural differences. The finding also revealed that the role of social workers can be contradictory as they work with both the mandatory contact tracing and they also provide conversational therapy (II). This contradiction can cause ineffectiveness in providing optimal consulting and support to the patients.

Sociodemographic differences between Swedish born and migrants living with HIV in Western region of Sweden showed that HIV-infected migrants were younger, more female and more with heterosexual route of transition compared to Swedish born (IV). Late diagnose was more common among migrants. There were also differences in self -reported QoL between the two groups. Migrant reported more often side-effects and more missed doses of antiviral drugs, compared to Swedish born (IV).

Discussion of main findings

A hybrid of access and adversity

The appreciation of free access to ART in Sweden can be seen in the light of the shortage of access to ART globally and in the countries of origin of the migrants. The UNAIDS statistic for 2018 shows that an average of 73% of PLHIV has global access to ART [4] although this is lower in HIV endemic countries. It differs between regions, from an estimated 40% in Western and Central Africa to approximately 60% in Sub-Saharan Africa. [4].

Study I, on the other hand, reports experiences of discrimination within general health care services outside of the Infectious Diseases Clinics among migrants living with HIV. This is confirmed by a study on ‘HIV-infected African parents living in Stockholm, Sweden’ [91]. Another study suggested that health care professionals in Sweden need to understand HIV-positive African parents’ cultural context in order to provide them with tailored medical advice and information. [92].

Discrimination within health care due to a lack of understanding or judgmental attitudes cause barrier to equal access to health care and is thus a key issue which needs to be addressed. To be seen, accepted and respected as an equal human being without discrimination and stigma is fundamental to human rights, trust, health and well-being of the individual. Moreover, Swedish health care policy emphasizes equal access to health care and equal treatment for every-one regardless of origin, culture and socio-economic status (93).

Further, the participants experienced the Swedish Communicable Diseases Act [60] as discriminatory causing stigma and limitation. The Swedish

Communicable Diseases Act is considered to be among the most prohibitive in the world [94]. A study found that the social dimensions of HIV are still extreme for PLHIV in the Swedish community, despite successful medical outcomes [95].

In addition, migrants living with HIV in Sweden are more vulnerable to the Swedish Communicable Disease Law [96]. Despite the low numbers of persons living with HIV who are condemned to prison, due to non-disclosure to the new sexual partner, the consequences for the convicted migrants living with HIV in Sweden could be extreme, since they may also be deported to their country of origin after serving the sentence [96].

The special report from The European Center for Disease Control [97] highlighted, among other things, discrimination towards migrants living with HIV, within the health care services in Europe, as being the obstacle to access to health care and HIV prevention. Moreover, a lack of cultural understanding among health care providers, in combination with a failure to integrate social support for migrants living with HIV raises institutional barriers and gives rise to discrimination [98].

Thus, in this context, it is crucial to integrate intersectional analysis into the studies of discrimination and barriers to health care services for migrants living with HIV, since multiple marginalized social categories cause multiple discrimination and oppression [25]. Migrants have legal access to health care in many European countries, but these legal rights are not always respected or available in practice [99].

The right to health care comprises the following four essential elements [100]: availability, accessibility, acceptability, and quality. Moreover, the right to health is considered by The United Nations as a fundamental human right [101]. One aspect of this right is defined as a system of health protection that provides equal opportunity for people to obtain health and well-being. It is also emphasized that, in order to obtain the right to health care services, PLHIV should be free from all the various forms of discrimination [102].

Fear of disclosure of HIV and stigma

Study III reported a fear of disclosure of HIV and perceived stigma as the constant expression which permeates the experiences of migrants living with HIV in the study. The consequences of this include increased loneliness, marginalization and stigma. However, stigma and its level of vulnerability varies in relation to the individual‘s socio-economic status, race, gender, and access to networks and education [103].

Fear of disclosure and stigma caused difficulties in finding a sexual partner and friends and causes a lack of social networks. As a result, many of the participants expressed their wish to find HIV-positive partner though they had difficulties in finding one due to the lack of a social network. This is confirmed by a study on the Swedish youth living with HIV. The study found that they refrained from sexual relations because they did not want to tell the new partner about their HIV-infection [104].

The interplay between the fear of disclosure and stigma creates a vicious cycle of stigma and fear of disclosure. HIV-stigma and marginalization tends to create distrust and fear of disclosure, which, in turn causes further stigma and marginalization [105, 106]. African migrants living with HIV in England, experienced racism and discrimination with HIV disclosure from health care providers, relatives and friends [107]. Stigma, fear of discrimination and rejection was associated with fear of disclosure in a systematic review on African migrants living with HIV in Europe [108]. On the other hand, the study from South Africa found that disclosure to trusted family members was crucial for social support [109].

However, the analysis of fear of disclosure and HIV-related stigma requires a holistic and profound analysis. For example, a systematic review found that this analysis needs to be associated with race, gender, and sexual orientation [110]. In particular, studies found that the negative consequences of HIV disclosure extend to rejection by sexual partners, family members and friends, losing a job, decline in the quality of health care services and even denial of care [111,112].

Although there is evidence on disclosure of HIV and its correlation with better mental and physical health with a decreased anxiety when the burden of secrecy is removed [108], it is necessary to widen the perspective of the analysis and its complexity. Due to the evidence that living openly as an HIV-positive and a migrant intersects with the multiple social marginalized identities [103].

Thus, measure should also be taken on multiple oppression, social marginalization and vulnerability in the context of fear of disclosure of HIV. For instance, the study revealed that African migrants are three times more exposed to HIV discrimination and stigma compared to white HIV-positive British people [113]. In this context, despite the fact that social support and empowering of migrants living with HIV is fundamental for well-being, this may be insufficient, due to the institutional and structural racism as well as xenophobia [110, 114,115]. In addition, difficulties in accessing housing and employment for migrants in Europe, cause even further obstacles [116].

Lack of social network

Lack of a social network and patient associations were issues of concern in the experiences of both migrants living with HIV (Study III) and also of HIV care givers (Study II). This result was also confirmed by the study on 'HIV-infected African parents living in Stockholm, Sweden' [91]. This study found that there were limited social networks for HIV-infected African parents. More than two-thirds of these had no relatives living in Sweden, and their social contact was basically limited to their children and partners [91].

A majority of the migrants living with HIV in the study (III) stated that they lived isolated, with limited social contact outside their formal contact with the authority and the staff at Infectious Disease Clinics, where their treatment was being managed. Lack of a social network was expressed as being the most challenging for single mothers with children. Because of the lack of a social network and patient associations, many of the participants wished for more time with their treating doctors and nurses in order to discuss their medical concerns and other relevant issues.

Providing an open and supportive environment for consulting and care to PLHIV could protect them from discrimination and stigmatization, and thus dignify their life [102]. This empowerment could, in turn increase the awareness among PLHIV of the need for measures to prevent transmission to others, and also to decrease the stigma and fear attached to HIV-testing [102]. Further, due to the evidence that social network is the basis of social relationships and has a crucial impact on health and well-being of people [117], the social network and support of PLHIV should be highly prioritized.

Vulnerability related to the migration status

Greater levels of support for patients who were within the migration process and for patients with different migration status required additional duties for some care givers beyond their usual duties (II). These needs were the result of the lack of a social network, language barriers, lack of community information that patients were faced with as well as the complex system of the migration process and its laws and regulations. For example, patients who received a refusal notice on their applications for their residence permit from the Migration Board were in need of support.

Although there was a lack of resources at the Infectious Disease Clinics in terms of this kind of support, some social workers made these additional efforts for humanistic reasons as they stated that these patients were highly vulnerable and had no existing social contacts and support (II). A study on HIV caregivers' experiences found that, in addition to an inclusive management structure in the process of treatment and care, it is crucial to provide sufficient human and material resources for care givers to enable them to provide optimal care to HIV-positives [118]. Another study with a medical anthropological approach illustrated that focusing on the living condition and socio-cultural practices and also being sensitive to individual and social needs can make health care delivery more effective [119].

On the other hand, there is a lack of a supportive strategy and policy, on macro-level, for the most vulnerable PLHIV in Sweden. This shortfall can be seen on the National Strategy Document against HIV /AIDS [55]. Swedish governmental HIV-funding [120, 121] is given each year to various municipal, state and voluntary organizations and aims to prevent HIV and support PLHIV. Considering the over-representation of migrants in HIV statistics in Sweden, and evidence on widespread vulnerability of migrants living with HIV, there is neither an inclusive approach nor a clear adopted, supportive and inclusive policy. Instead, a substantial part of the governmental funding on HIV AIDS is allocated to administration and bureaucratic work [121].

Many studies have already shown the different phases of migration and especially post- migration phase in particular can deteriorate an individual’s health and well-being [30,31, 32]. Moreover, HIV –infection causes a complex system of vulnerability from pre- migration to post-migration. More specifically, the lack of a social network, exclusion, and lack of access to services experienced by migrants living with HIV cause multiple vulnerabilities [122].

Thus, allocation of resources for treatment, empowerment and the well-being of migrants living with HIV should be based on a holistic view. These should be based on patients’ experiences in order to meet their needs. Further, resources should be understood in term of the demand they individually experience in their encounter with the new society [123].

Resilience

The study (III) revealed the struggle of migrants living with HIV for a dignified life in the face of vulnerability. Resilience is defined as the ability to recover from adversity [124]. The theoretical conceptualization of resilience involves both individual’s capacity to overcome adversity and social support surrounding individual’s life [125, 126]. It is regarded as a dynamic phenomenon that varies among different cultures [126].

Despite the negative impact of HIV on physical, psychological, and social health and well-being, evidence has revealed that PLHIV are both vulnerable and resilient [127]. The study found that even though HIV- disclosure among Saharan African women living in Switzerland is highly stigmatizing, they choose disclosure and non-disclosure on the basis of their individual rights and obligations [128]. For instance, some women choose disclosure in order to challenge racism and discrimination. The evidence revealed that women were not only victims but were also agents in their own lives [128].

This finding is also confirmed by evidence from the WHO on vulnerability and resilience in the context of health inequalities among migrants in Europe [28]. They state that, despite vulnerability, migrants should not be seen as passive victims as they can be resilient. To address health inequalities among migrants within European countries it is crucial to understand the inequalities that produce exclusion, vulnerability, and resilience. [27, 28].

Thus, a paradigm shift is necessary on how the powerful and privileged view the marginalized and oppressed. This is required as a basis for health equality and to strengthen individuals as free agents with the potentials to be resilient and empowered.

Sociodemographic differences between migrants and Swedish born living with HIV

The quantitative InfCare HIV study (IV) revealed socio-demographic differences between migrants and the Swedish-born living with HIV. The majority of migrants were women, they were younger, and had heterosexual route of HIV. This pattern is confirmed by the studies showing increased HIV-infection among young women in high prevalence countries as well as among ethnic minority women in Western countries, due to the socioeconomic conditions, gender inequality and lack of access to sexual and reproductive health [129, 130].

Gender inequality both contributes to the spread of HIV, and reduces the ability of women and girls to cope with the epidemic. Lack of access and resources to sexual and reproductive health is a challenge for the majority of women, especially marginalized women, globally, causing sexually transmitted diseases and also maternal and neonatal mortality and morbidity [131].

In addition, evidence reveals that women's inability to negotiate safe sex because of unequal power relationships with men makes them vulnerable to HIV-infection [129,132]. Hence, empowering women and enhancing their sexual and reproductive health and rights is a key issue for improving equality in health and well-being. It is also crucial in the global context of HIV-prevention and care [4].

Differences in treatment outcome and QoL between migrants and Swedish-born people living with HIV

Study IV revealed higher levels of side-effects and more frequent missed doses of antiviral drugs among migrants compared to the Swedish born. This can have a negative impact on the treatment outcomes and QoL. It also revealed that a larger proportion of migrants had detectable viral loads and also lower median CD4 nadir. This result is confirmed by studies from Western Europe showing that late diagnosis and missed doses result in poorer treatment outcomes among migrants compared to native-born individuals in Europe [133,134].

Many studies have already shown a correlation between low socio-economic status, poor HIV treatment outcome and also higher HIV-related mortality as the result [135, 136,137]. Moreover, higher mortality and morbidity among migrants and ethnic minority groups living with HIV in Western countries are also well-documented [133, 138].

Further, differences in self-reported QoL revealed that larger sub-groups of migrants in the study (IV) had low satisfaction with their physical health compared to Swedish born. This could be explained by late diagnosis among a sub-group of migrants with a more advanced disease. This is reflected in the lower median CD4 nadir among migrants compared to Swedish born in the study (IV). Studies have also confirmed correlation between lower CD4 nadir and reduced physical health [139,140,141].

Another explanation for lower self-reported physical health is related to increased side-effects among migrants compared to Swedish-born in the study (IV). This could also be explained by the less use of integrase inhibitors in treatment of migrants compared to Swedish-born. These integrase inhibitors are among the most recent antiviral drugs available, having a high efficacy and fewer side-effects but are more expensive. In addition, a higher frequency of side-effects might explain the reporting of more missed doses of antiviral drugs among migrants in the study (IV).

The somehow unexpected finding that migrants had a higher level of satisfaction with sexual health compared to Swedish-born in the Study IV could be due to a lower expectation of sexual relationships among migrants. This could also be explained by a significantly higher number of migrants who refrained from responding to the question about their sexual health in the health survey questionnaire (see Table 2).

Moreover, HIV care givers also reported difficulties discussing sexual issues with migrant women in Study II. This is confirmed by other reports showing difficulties and obstacles for many migrant women to access sexual health information, due to the dominance of the Eurocentric approach that tends to ignore the sensitivity, and complexity of this issue related to diverse cultural contexts [142,143].

It is therefore of importance to improve cultural sensitivity and extend critical knowledge in combination with inclusive and peer-based interventions within the framework of sexual and reproductive health for ethnic minority women, in order to enhance their access to sexual and reproductive health. Since the population of migrant women living with HIV is more vulnerable in this context, they should be given high priority.

CONCLUSIONS

This thesis has contributed to new knowledge relating to migrants living with HIV and their experiences. The conclusions are summarized below:

- Free access to ART is necessary but not sufficient for migrants living with HIV in order to experience well-being in their lives.

- Structural discrimination towards migrants living with HIV within the Swedish health care system was reducing the well-being of migrants.

- Experiences of lack of a social network and support, lack of patient associations and the highly stigmatized life situations of migrants living with HIV have reduced their well-being resulting in loneliness and a strong desire for close friends and a partner.

- Migrants living with HIV were also resilient and showed that they could cope in their daily struggle for a dignified life, despite the stigma and the lack of social resources.

- Lower CD4-nadir and more frequent detectable viral load among migrants living with HIV compared to the Swedish-born indicate poorer treatment outcomes for these individuals. The migrants also had increased side-effects and more missed doses of their antiviral drugs.

- The migrants had higher satisfaction with their sexual health and a subgroup of them had lower satisfaction with their physical health.

METHODOLOGICAL CONSIDERATIONS

Trustworthiness is the qualitative criteria for all qualitative research and concerns credibility, transferability, dependability and confirmability [144]. In Study I-III measures were taken to establish trustworthiness.

Credibility is defined as the relationship between empirical data and categories [144]. This was ensured through investigator triangulation in the process of data analysis. In practice, this meant that the research team discussed regularly the code, concepts and categories as well as the core-category related to the data analysis [144]. Further, data analysis of the studies I-III started with data collection and data analysis continued until no new information was added [84, 85]. This has also ensured the credibility of Studies I-III.

Moreover, the pervading description of the research process in Study I-III including study design, data collection and data analysis was essential to enhance the credibility, and the quotations in the subcategories ensured the confirmability.

Transferability in qualitative methods refers to the results of research that can be transferred to other contexts and groups with similar characteristics [144]. The participants in Studies I and III had different backgrounds, socio-economic, age and gender, although they had many similar experiences in terms of their life situation within the sharing context of living as migrants with HIV in Sweden. Thus the results can be transferred to similar groups and contexts [144].

Nevertheless, the exploratory qualitative Studies I-III have expanded our knowledge of migrants living with HIV as well as care givers' experiences of the care provided for migrants living with HIV. Qualitative research designs are essential to provide policy makers and health professionals with the narrative knowledge needed for developing quality of care and treatment and for improving access to care [145].

However, the participants in Study II included only the nurses and social workers who work at the Infectious Disease Clinics. The experiences of the physicians who also work in the field were not included in this study. This needs to be investigated further in greater detail.

Study IV was a quantitative study, thus the criteria for the quality of this study was based on validity and reliability [146]. Validity refers to the extent to which a concept is precisely measured. Reliability is the extent to which a research instrument consistently produces the same results if used repeatedly in the same situation. The validity and generalizability of the study were established by the selection procedure that encompassed all patients registered at the Infectious Disease Clinics in the Western region.

In the Study IV, the migrants’ lower rate of responses to the health survey questionnaire in InfCare HIV, compared to the Swedish-born caused some limitations, when comparing the two groups. The health survey questionnaire was available in English and Swedish only and may result in selection bias.

On the other hand, our study is the first in Sweden to compare the differences in QoL and treatment, and socio-demographic differences between migrants and Swedish-born living with HIV. This study is also the first study to indicate that there are limitations to InfCare HIV in terms of a lack of response to the QoL questionnaire from migrants living with HIV. This needs improvement for the purposes of further information gathering and future evaluations.

Moreover, the health survey questionnaire in InfCare HIV needs improvements in order to be culturally and socially adapted. This is especially important for sensitive issues such as sexuality and mental health because the responses to these questions were low among the migrants living with HIV.

FUTURE PERSPECTIVES

Future studies in the context of migration and HIV based on participatory research are warranted. Despite the numerous studies in this field globally, the need still remains to change the perspective of HIV research to include those individuals who experience multiple oppression and marginalization in this context. Hence it is crucial to have a greater focus on the experiences and needs of PLHIV who experience different degrees of vulnerability in order to provide holistic care, support and enable the empowerment of these individuals.

Improved knowledge through critical studies and analysis that include the experiences of HIV-related stigma in living with sexism, racism, and homo/transphobia should be prioritized. There is plentiful evidence as to the structural barriers to health and social determinants of health, but it is crucial to identify the structural barriers within different contexts.

Furthermore, considering that theories on intersectionality in HIV and health inequality are well-developed, they should be incorporated into the research that addresses the structural barriers and health inequalities on micro, meso, and macro levels.

Moreover, there are insufficient studies exploring the experiences of migrant women living with HIV, based on the theoretical framework of black feminism and post-colonial theories. Since migrant women living with HIV generally include women of color with multiple marginalized social identities resulting in vulnerability, it is necessary to provide new information and knowledge to enable the empowerment of these individuals. This is essential since the evidence points to the fact that the majority of the migrant population living with HIV in Sweden is women.

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SAMMANFATTNING PÅ SVENSKA

Det övergripande syftet med denna avhandling var att fördjupa kunskaper om livssituationen hos hiv-positiva individer med invandrarbakgrund avseende upplevelser av livet i Sverige och kontakter med hälso- och sjukvården. Avhandlingen bygger på fyra delstudier.

Studie I var en Grounded Theory studie om erfarenheter av mötet med svensk hälso-och sjukvård. Semi-strukturerade intervjuer utfördes med 14 deltagare, sju kvinnor och sju män i åldrarna 29-59 år, från olika delar av regioner i världen (Afrika n=10, Sydostasien n=1, Sydamerika n=2, Östeuropa n=1). Deltagarna upplevde diskriminering inom den allmänna sjukvården samtidigt som de uppskattade fri tillgång till avancerad behandling med bromsmediciner mot HIV på infektionsklinikerna.

Studie II var en explorativ kvalitativ studie med focus-grupps intervjuer, analyserade med kvalitativ innehållsanalys, avseende vårdpersonalens erfarenheter av arbete med HIV-positiva patienter med invandrar bakgrund vid tre infektionskliniker i västra Sverige.14 sjuksköterskor och kuratorer, samtliga kvinnor, intervjuades. De rapporterade utmaningar avseende begränsad tid för kommunikation med och stöd till patienter med invandrarbakgrund vid klinikerna. Dessa patienter behövde mer tid och socialt stöd på grund av olika grader av utsatthet, bland annat i samband med ovisshet om och utmaningar vid kontakter med Migrationsverket för uppehållstillstånd, erhållna avslag från Migrationsverket och svårighet i kontakt med andra myndigheter såsom Försäkringskassan och Arbetsförmedlingen. Vidare, orsakade brist på såväl socialt närverk som patientorganisationer ännu mer utsatthet hos dessa patienter.

Studie III var en explorativ kvalitativ studie med semi-strukturerade intervjuer, analyserade med kvalitativ innehållsanalys, som studerade upplevelser av livssituation utanför hälso- och sjukvården hos HIV-positiva deltagare med invandrarbakgrund. Deltagarna i studien bestod av samma deltagare som i studie I. Vi fann utsatthet i sociala relationer på grund av upplevt stigma, ensamhet, utanförskap och brist på socialt nätverk och stöd. Rädslan för att bli avslöjad med att ha HIV-infektion var också omfattande och orsakade ännu mer ensamhet och svårigheter att hitta partner eller nära vän. Dessa individer visade också tecken på motståndskraft i sin strävan att hantera sina existentiella osäkerheter och upprätthålla ett liv med värdighet, samt i behovet av att se positivt på livet.

Studie IV var baserad på data från kvalitetsregistret InfCare HIV bearbetat med kvantitativ analys. Syftet var att undersöka om det fanns skillnader i livskvalitet, vård och behandling mellan HIV-positiva patienter med invandrarbakgrund och svenskfödda på infektionsklinikerna i Västra Götalandregionen. 839 patients, varav 540 med invandrarbakgrund och 299 svenskfödda var inkluderade i studien. En undergrupp av patienterna med invandrar bakgrund hade lägre tillfredsställelse med sin fysiska hälsa jämfört med svenskfödda. En högre andel av patienter med invandrarbakgrund svarade att de var tillfredsställda med sin sexuella hälsa. Samtidigt var antal patienter som avstod från att svara på frågan om sexuell hälsa högre bland patienter med invandrarbakgrund. Sociodemografiska skillnader visade att patienter med invandrabakgrund bakgrund var yngre (medianålder 31 år mot 37 för svenskfödda), större andel kvinnor (53.7% mot 17.7% bland svenskfödda) och hade oftare heterosexuell smittväg (67.4% mot 43.5 % bland svenskfödda). Vidare hade patienter med invandrabakgrund högre förekomst av hepatit B (4.5% mot 1.0%) och missade oftare doser av intag av sina HIV-läkemedel 15,4% mot 5,6%), samt hade oftare biverkningar av behandlingen (24.4% mot 15.3%)

Slutsatser: Nya strategier och resurser behövs för att höja kunskaperna om HIV, migration, rasism, och utsatthet inom den allmänna hälso- och sjukvården samt andra sociala arenor, i syfte att minska stigma och diskriminering riktade mot HIV-positiva i allmänhet och mot HIV-positiva med invandrarbakgrund i synnerhet.

Vidare behövs individanpassat socialt stöd som minskar marginalisering och utanförskap och förstärker socialt nätverk bland HIV-positiva individer med invandrarbakgrund. Stödet bör utformas utifrån ett holistiskt perspektiv samt utifrån patienternas själv-definierade problem och behov.

Extra resurser för individanpassad vård och behandling på infektionsklinikerna behövs i syfte att effektivisera behandling och höja livskvalitet för dessa patienter. Bland annat behövs mer tid för kommunikation och information till patienterna och inte minst, mer tid för samverkan med andra sociala aktörer Detta kan vid framgång även leda till minskade vårdkostnader för patienterna.

Nyckelord: HIV-positiv, invandrarbakgrund; livsituation; hälso- och sjukvård, Sverige

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